Transforming Biomedical Informatics and Health Information Access

Don Lindberg and the U.S. National Library of Medicine

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During his 31-year tenure as director of the U.S. National Library of Medicine (NLM), Donald A.B. Lindberg M.D. dramatically increased access to knowledge about health issues, medicine, medical care, the health professions, and health literacy. As an enthusiastic visionary with a plan, his aim was to bring about a more efficient transfer and use of information and data. Dr. Lindberg and the NLM helped transform and reshape medicine and the health system in the 20th and 21st centuries. Dr. Lindberg envisioned, encouraged, and supported the development of electronic health records and telemedicine. Coupled with the evolution of the Internet, these technologies made health systems more efficient for research, the delivery of clinical services, the education of health professionals, bioethics, improving the public's health literacy, and disease prevention strategies. Dr. Lindberg also was committed to enhancing the capacity of underserved and minority populations to make use of NLM's health information resources.

Transforming Biomedical Informatics and Health Information Access is a tribute to Don Lindberg and the NLM. The book is divided into four sections. The first documents the advances in biomedical informatics during Dr. Lindberg's career, emphasizing the contributions made by teams of talented individuals at the NLM. The second section describes how the NLM's creation of new methods of access to diverse biomedical databases improved information access for healthcare professionals, biomedical researchers, and the public. The third section explains how NLM's outreach programs improved access to health information among underrepresented audiences and communities. The more informal fourth section provides brief memoirs about Dr. Lindberg's life, character, and humanism.

TRANSFORMING BIOMEDICAL INFORMATICS AND HEALTH INFORMATION ACCESS: DON LINDBERG AND THE U.S. NATIONAL LIBRARY OF MEDICINE

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Transforming Biomedical Informatics and Health Information Access: Don Lindberg and the U.S. National Library of Medicine

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Cover photo: In his office at the U.S. National Library of Medicine (NLM), Donald A.B. Lindberg M.D. shows his grandson Chris Lindberg (then age three) how to find information on the Internet. The photo captures one of NLM's and Dr. Lindberg's key contributions – providing quality health information to everyone. The image also depicts Dr. Lindberg's skills as a teacher and mentor, which are discussed widely within this book. The now-adult Chris Lindberg is the author of a memoir in section four of this book. The cover photo was taken in 1999 by Roger Vilsack and is courtesy of NLM. The photo is a favorite among the Lindberg family and was used in many NLM publications for more than two decades.

Foreword

Louis W. SULLIVAN M.D.[1]
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U.S. Secretary of Health and Human Services, 1989–1993

During his thirty-one-year tenure as director of the National Library of Medicine (NLM), Donald Lindberg dramatically increased access to knowledge of health issues, medicine, medical care, the health professions and health literacy.

He helped to bring Americans into the clinic, the laboratory, the hospital, the body, the cell and the molecule.

As a visionary with a plan and enthusiasm for more efficient transfer and use of information and data, Don helped to transform and reshape medicine and the health system in the twentieth and twenty first centuries. He envisioned, encouraged, and supported the development of the electronic health record and telemedicine. With these technologies and the increasing evolution of the internet, our nation's health system was made more efficient for research, the delivery of clinical services, health professions education, bioethics, improving the health literacy of the public, and – for health promotion – disease prevention strategies.

With Don Lindberg's leadership, libraries in hospitals and in health professions schools became dynamic centers for biomedical information and health education.

Don was committed to equal access of health information for all in our society – rich or poor, male or female, young or old, African American, Latino, or Native American-Pacific Islander. He worked to see that all views were represented on the NLM Board of Regents, around his conference table and among his professional staff. I enjoyed my years as a member of the NLM Board of Regents, working with Don on policies at NLM and planning for future developments.

To work with Don Lindberg was a joyful, uplifting experience. He saw the dissemination of scientific and technical information as an opportunity for service – to people, to institutions and to systems. He was always inspiring.

Don's impact on the National Library of Medicine, on healthcare systems, and on the world of biomedical informatics and computational biology was profound. His legacy is strong. We are all beneficiaries of his vision, his life's work and his dedication to constant improvement and service to others. This publication – the work of Don's peers and colleagues – shows the breadth and depth of Don Lindberg's influence on American medicine, medical communications, biomedical informatics, the health of the American people and to global health.

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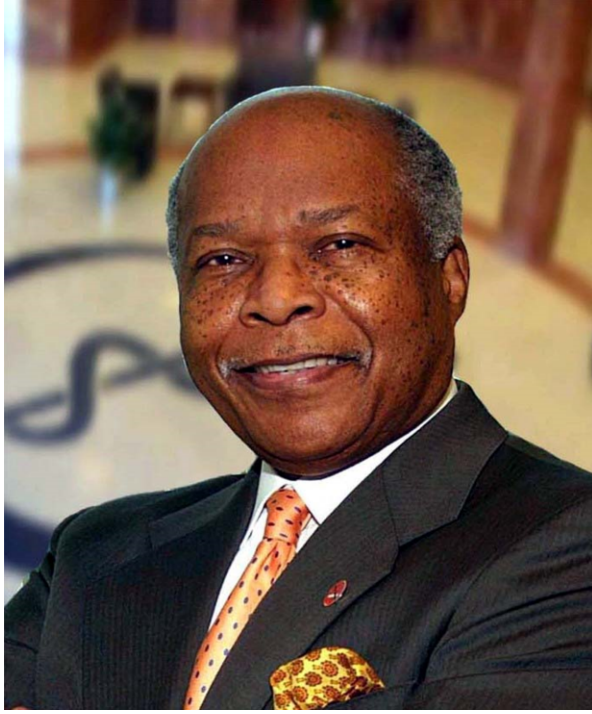
Louis W. Sullivan M.D. President Emeritus, Morehouse School of Medicine;
U.S. Secretary of Health and Human Services, 1989–1993

Preface: Transforming Biomedical Informatics and Health Information Access: Don Lindberg and the U.S. National Library of Medicine

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Abstract. This preface introduces the book, *Transforming biomedical informatics and health information access: Don Lindberg and the U.S. National Library of Medicine*. The preface includes information about the book's development process and intended audiences. The book's contributions comprise four thematic sections. The first section documents advances in biomedical informatics during Dr. Lindberg's career, emphasizing contributions made by teams of talented individuals at the U.S. National Library of Medicine (NLM). The second section describes how NLM's creation of new access methods to diverse biomedical databases improved information access for health care professionals, biomedical researchers, and the public. The third section explains how NLM outreach programs improved access to health information among underserved audiences and communities. The fourth (and more informal) section provides brief memoirs about Dr. Lindberg's life, character, and humanism.

Keywords. U.S. National Library of Medicine, Donald A.B. Lindberg, history of biomedical informatics, Randolph A. Miller., Betsy L. Humphreys, Elliot R. Siegel, Robert A. Logan, Mary M. Lindberg, U.S. National Center for Biotechnology Information

1. An Era That Transformed Biomedical Informatics and Access to Health Information

This book describes how a series of initiatives from 1984–2015 by the U.S. National Library of Medicine (NLM) under Donald A.B. Lindberg M.D.'s leadership generated a remarkable transformation in biomedical informatics and access to health information. NLM extended access to the biomedical literature for health care professionals, biomedical scientists, and the public, including underserved communities [1]. Via free MEDLINE and NLM's other Internet-based tools, anyone in the world could directly access the medical literature and a growing collection of informative databases [1–2].

NLM's intramural and extramural initiatives accelerated its institutional evolution and advanced the field of biomedical informatics. For example, NLM (via its National Center for Biotechnology Information – NCBI) introduced Internet-based tools to access vast curated, searchable, and cross-indexed data repositories [3]. NCBI's aggregate services increased the cooperation among researchers worldwide and optimized the

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capabilities of scientists to remain current [3]. During the next three decades, these services became foundational to research in genetics, genomics, molecular biology, computational biology, and related biosciences areas [3].

NLM fostered Internet-based support for patient health education by launching consumer health information websites, such as MedlinePlus.gov and Genetics Home Reference [4]. NLM's evidence-based consumer health services, some of which are in English and Spanish, also provided access to repositories of health knowledge from NLM's other Internet-based resources [4].

Parallel to these developments, NLM initiated an array of outreach programs to enhance access to health information among medically underserved populations. NLM's outreach initiatives sought to improve population health, boost health equity and health literacy, expand health knowledge, as well as enhance patient decision-making and self-efficacy [5]. One of NLM's outreach projects, Native Voices, introduced the broader public to some of the concepts of health, wellness, and illness held by indigenous peoples in the U.S. [6–7].

This book introduces these as well as other developments and contextualizes many of NLM's accomplishments. In addition, the book notes the contributions and influence of Dr. Lindberg, NLM's director from 1984–2015, who was the common denominator in all NLM's diverse efforts [1,5,8–9].

2. The Book's Creation and Intended Audiences

Dr. Lindberg retired as NLM's director in March 2015 at age 81. He died in August 2019 at age 85. The work on this book began about eight months after his death and continued through fall 2021.

Over dishes of trashcan (flavor) ice cream, Don first discussed a book with me at The Pink Pony in Boca Grande, FL in late January 2019. Trashcan is the ice cream equivalent of 'debris' in New Orleans' Po-Boy sandwich restaurants (...*just add whatever ingredients are lying around*). At the time, I was 15 months away from completing a second book on health literacy research and practice with Elliot Siegel Ph.D. [11]. (Dr. Siegel directed many of NLM's outreach initiatives when he was NLM's Associate Director for Health Information Programs Development. I worked with Don for five decades and represented him via NLM's 'Director's Comments' podcast every Friday for several years.).

After inquiring about the then-in-progress health literacy text, Don surprised me by initiating an informal discussion about a hypothetical book to summarize some of NLM's initiatives between 1984–2015. In a 'what if' conversation, Don suggested three themes: NLM's contributions to the field of biomedical informatics; NLM's leadership in providing access to health information for health providers and the public; and the Library's outreach efforts. Although the areas Don initially proposed became three of the current book's four sections, I did not return to Don's ideas until 16 months after the trashcan chat (and eight months after his death).

The current book's fourth section – devoted to memoirs about Dr. Lindberg – emerged from suggestions by Mary Lindberg and members of the Lindberg family when I began in earnest to organize a book proposal in April 2020. Given our previous editorial collaborations, I asked Siegel to help expand a rough draft into a formal book proposal.

Siegel and I – with Mary Lindberg's consultation – quickly agreed that the book's proposed sections about biomedical informatics and access to health information

required co-editors with internationally respected field knowledge. The disciplinary gaps were addressed when Betsy Humphreys M.L.S., former NLM Deputy Director and Acting Director (after Dr. Lindberg's retirement), and Randolph Miller M.D., the emeritus Cornelius Vanderbilt Professor of Biomedical Informatics at Vanderbilt University and former editor-in-chief of the Journal of the American Medical Informatics Association, joined Siegel and I in spring 2020. The new team of four co-editors soon created a book proposal with an expanded range of specific topics. The co-editor of each section, then, identified appropriate authors for each proposed chapter and personally invited candidates to participate. Few persons declined and most expressed enthusiasm for the initiative.

In early summer 2020, the co-editors asked IOS Press to consider a book proposal because of the publisher's active history in the field of biomedical informatics. and IOS's publication of the aforementioned books on health literacy that I edited with Siegel [11–12]. IOS Press expressed interest within 36 hours and the trashcan chat advanced into a working book by summer 2020.

During the process of developing manuscripts from July 2020 to September 2021, the co-editors found most of the chapters focused on the impact of selected NLM initiatives between 1984–2015 with a parallel emphasis on Don's personal contributions in each area. This reinforced the book's editorial direction, which is discussed below.

The book is intended for biomedical researchers, students of the health sciences, and healthcare practitioners. It covers topics in biomedical informatics, consumer health informatics, health disparities, health literacy, public health, molecular biology, health sciences librarianship, history of medicine, and information technology. It will be of value to historians of biomedicine, medical institutional administrators, governmental legislators and administrators, health services research practitioners, and persons interested in outreach to medically underserved populations.

The book's four co-editors salute the 65 authors who volunteered their time and attention to complete the volume despite demanding deadlines. The co-editors deeply appreciate the cooperation and collaboration of the Lindberg family (and especially Mary Lindberg) in the planning and development of this book. Mary Lindberg attended some editorial meetings, co-prepared the photo essay contribution, and gave contributors access to Don's library. Mary also best summarized why many of the book's contributors were so eager to participate. 'It illustrates both gratitude and grief,' she said. The co-editors thank IOS Press (especially Paul Weij and Kairi Look @ IOS) for their continuing interest and responsive collaboration. A salute as well to The Pink Pony ice cream parlor, which I expect to revisit.

3. Overview of the Book's Contents

The book's cogent foreword is from Louis Sullivan M.D., the former Secretary of the U.S. Department of Health and Human Services. The first three sections of the book focus on NLM's activities and their impact on biomedical informatics and health information access. Those sections indicate how the advancement of NLM initiatives often was inspired by Dr. Lindberg's vision, encouragement, interest, and involvement [1,5,8]. They document his legacy.

Consistent with the suggestion that NLM under Don orchestrated a transformation in biomedical informatics and access to health information, section four of the book introduces readers to *him*. Section four provides insights about Don's life, character, and

humanism, mostly through brief memoirs. Collectively, these contributions help discern the multidisciplinary and multidimensional characteristics that furnished the foundation of Don's leadership abilities [9].

To save space and eliminate redundancy, each of the book's 32 chapters, 20 memoirs, and four other contributions are introduced at the start of each of the book's four sections [1,5,8–9]. A brief description of all four sections is provided below.

The book's first section, edited by Dr. Miller, introduces the advances in biomedical informatics concurrent with Dr. Lindberg's career and contributions [8]. Section one focuses on the growth and transformation of biomedical informatics, especially during Dr. Lindberg's term as NLM Director, and his role and influence. It contains 13 chapters, each written by authors with domain expertise who worked with Dr. Lindberg – either for or with the support of NLM. Section one's contributors represent more than a dozen higher educational and biomedical institutions in the U.S. and internationally, including NLM and the National Human Genome Research Institute within the U.S. National Institutes of Health.

The book's second section, edited by Ms. Humphreys, describes how NLM enhanced the capacity of health care professionals and the public to access and understand biomedical research and information – and expanded the roles of medical librarians [1]. Section two's eight chapters focus on how NLM led a transformation to provide health information to medical professionals and the public, and expand the role of medical libraries, librarians, and health information specialists from 1984–2015. Section two's contributors represent several higher educational institutions, NLM, the Veterans Health Administration, the Medical Library Association, and the former American Publishers Association, among others. Ms. Humphrey's introductory chapter also provides an insightful before-and-after comparison of the remarkable changes in NLM's array of services and their use during Dr. Lindberg's directorship [1].

The book's third section, edited by Dr. Siegel, chronicles NLM's outreach to improve access to health information among underserved audiences and communities [5]. It contains 11 chapters, written by authors who worked for (or with) NLM on the described initiatives during Dr. Lindberg's tenure. Section three's contributors represent four higher educational institutions, the Southcentral Foundation, NLM, and some associations. Two chapters cover NLM's international efforts in South America and Africa [12–13]. Several chapters chronicle U.S.-based outreach efforts for underserved audiences (African Americans, Hispanic Americans, Native Americans, Alaska Natives, and Native Hawaiians), the affected AIDs community, and institutions (Historically Black Colleges and Tribal Colleges) [14–16]. One chapter provides a background history of NLM's outreach to health consumers [17]. One chapter explains how NLM's outreach efforts were assessed, and another underscores the many contributions of NLM's network of medical libraries to outreach activities [18–19].

Section four contains 20 memoirs about Dr. Lindberg's life, character, interests, and passions [9]. Section four includes a Resource Guide about Dr. Lindberg's life and career, an essay about the influence of his home library and leadership traits, and a few of his photographs [20–22]. In contrast to the contributions elsewhere in the book, section four's 20 memoirs are brief, more conversational, and sometimes personal. Section four's memoirs are divided into contributions from family members, lifelong friends, biomedical informatics colleagues, and NLM peers. Insightful and sometimes poignant chapters describe the influence of his home library, his leadership traits, and add some of his photographs. I edited section four.

While the co-editors tried to make the book as comprehensive as possible, it is not exhaustive. Some of NLM's initiatives between 1984–2015 are not mentioned, and some programs receive more attention than others. A few of NLM initiatives that are not covered in full include: a) ClinicalTrials.gov; b) PubMed Central (PMC); c) the Library's efforts to organize and provide emergency disaster information to first responders, such as WISER, and the Disaster Information Management Research Center; d) programs to provide toxicological/environmental health information, such as ToxNet and ToxMap; and e) portals to access health services research. Similarly, some outreach initiatives are not detailed, such as a pioneering program between NLM and the Association of Health Care Journalists to improve the use of NLM's health information services by journalists, which Dr. Lindberg supported enthusiastically.

4. Why Readers Should Find This Book to Be Useful and Informative

The book provides interesting historical details that currently are not well known in the biomedical and health informatics community. Readers will find value in the book's content because of the reach and scope of NLM's initiatives and the underlying values and leadership that inspired them.

The book's co-editors hope readers will discover a range and depth of activities that transformed a field and provided pioneering services to health care professionals, scientists, and the public. The book also contextualizes NLM's impact on health care professionals, the development of the field of biomedical informatics, the biosciences, universal access to health information for health professionals and the public, and 21st century progress in medical care. In some cases, these intersections and connections are discussed for the first time. The book's contributions additionally illustrate how NLM transformed a discipline, enabled progress in significant aspects of health care delivery, rejuvenated itself, and therapeutically aided health care providers, scientists, and the public – all at the same time.

Overall, the book's aggregate contributions provide more than a tribute to the significant contributions of NLM's staff, Dr. Lindberg, and others with whom he worked. The editors hope readers will descry how one institution (with exceptional leadership) abetted and inspired the advancement of a scientific/medical/professional paradigm that has improved the health and lives of millions.

Finally, the book's contents provide a primer on imaginative administration and the use of public resources to advance science, medicine, health, and the public interest. For readers who believe in the joy of transformation, collaboration, constructive leadership, and creative stewardship, this book has a story to tell.

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Contents

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Section One

Biomedical and Health Informatics:
The Transformative Roles of
Donald A.B. Lindberg and
the U.S. National Library of Medicine

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Donald A.B. Lindberg and the U.S. National Library of Medicine Transformed Biomedical and Health Informatics

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Abstract. This overview summary of the Informatics Section of the book *Transforming biomedical informatics and health information access: Don Lindberg and the U.S. National Library of Medicine* illustrates how the NLM revolutionized the field of biomedical and health informatics during Lindberg's term as NLM Director. Authors present a before-and-after perspective of what changed, how it changed, and the impact of those changes.

Keywords. U.S. National Library of Medicine, Donald A.B. Lindberg, Biomedical Informatics, Health Informatics.

In memory of Harold M. Schoolman M.D. 1924-2009. Deputy Director for Research and Education, U.S. National Library of Medicine, 1970-1999.

1. Introduction

From the early 1980s to 2015, the computing landscape in the United States evolved from expensive, privately accessed mainframes to ubiquitous, inexpensive desktop computers and powerful handheld devices. During that time, computer input mechanisms progressed from punched cards and keyboards to mouse clicks, touch screens, and speech recognition. Person-to-person phone communication morphed from hard-wired rotary dial telephones (and coin-operated telephone booths!) to compact, hand-held lightweight multifunction cellular devices. Remote connections to computing resources advanced from slow, fee-for-service commercial connections using acoustic modems to free high-speed internet access. During the tenure of Donald A.B. Lindberg M.D. as its Director from 1984 to 2015, the U.S. National Library of Medicine (NLM) introduced complementary transformations that radically altered and advanced the landscape of biomedical and health informatics in the United States. The chapters of the Informatics Section of the book, *Transforming biomedical informatics and health information access: Don Lindberg and the U.S. National Library of Medicine* document these transformations [1-12].

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Lindberg's early years demonstrated his ability to recognize and solve challenging problems. This foreshadowed his later informatics accomplishments. In *A scientific mind embraces medicine: Donald Lindberg's education and early career*, Kingsland and Kulikowski describe Lindberg's formative years at Amherst, Columbia University, and at the University of Missouri [1]. Lindberg pioneered development of laboratory information systems. He installed terminals on hospital wards to deliver laboratory results to clinicians, and correlated microbiology culture results with antibiotic sensitivities. Using the College of American Pathologists' *Systematized Nomenclature of Pathology* to cross-index information from multiple sources, Lindberg oversaw a team that developed a computer-based fact bank. He and a colleague engineered a modified 8-track stereo audio cartridge system that could provide dial-up answers to medical questions posed by underserved rural patients and their families. Lindberg also contributed to development of early computer-based diagnostic decision support tools. His creativity and accomplishments led to his selection as Director of the NLM in 1984. At NLM, Lindberg repeatedly applied, on a much larger scale, the schema he developed in Missouri: identify a novel challenging problem, locate and combine disparate resources needed to address the problem, and provide creative ways to access the information.

In *Lindberg, pioneer in biomedical and health informatics: his involvement in creating professional organizations*, van Bemmel, Ball and Shortliffe reveal another aspect of Lindberg's character - his role as a visionary and highly capable leader [2]. They observe that throughout his career, Lindberg surrounded himself with teams of top researchers and superb staff. Early in his career, he held positions on the Boards of the American Association for Medical Systems and Informatics (AAMSI), and the Symposium on Computer Applications in Medical Care (SCAMC). With colleagues, Lindberg played a critical role in founding the American College of Medical Informatics (ACMI). Those activities, combined with his leadership role at the NLM and his contributions as the American representative to the International Medical Informatics Association (IMIA), prepared him to become the logical choice to serve as the founding President of the American Medical Informatics Association (AMIA). Lindberg not only could unite disparate information resources; he could effectively organize people as well.

2. How NLM Laid the Foundation for Professional and Institutional Growth in Biomedical and Health Informatics

Lindberg's approach to integrating, cross-referencing, and providing new means of access to biomedical information characterized many of the projects that NLM implemented under his visionary leadership.

The national informatics landscape prior to Dr. Lindberg's arrival at NLM consisted primarily of individual investigator-initiated laboratories in isolated academic settings [13]. A small number of institutions had developed one-of-a-kind clinical information systems that were used locally. Academic medical centers had typically placed their computing facilities under the purview of Chief Financial Officers (CFOs) since billing and accounting were critical to their domain. Most CFOs saw little benefit in diverting

computer resources to support healthcare research or medical libraries, or to make direct interventions in care delivery. The academic institutions harboring early informatics faculty members had difficulty understanding how to value and promote individuals whose seemingly opaque work did not fit neatly into existing criteria for advancement.

Several trailblazing NLM projects made key contributions that changed this situation. Their nationwide (and often global) impacts facilitated establishment of biomedical informatics as a modern, professional discipline [3-12,14]. Lorenzi and Stead describe the development and evolution of the Integrated Academic Information Management Systems project in *NLM and the IAIMS Initiative: cross-institutional academic/ advanced systems contributing to the evolution of networked information and resources* [3]. Following a 1962 study that indicated academic medical libraries were underutilized, the Medical Library Assistance Act (MLAA) of 1965 authorized NLM to provide resources to medical libraries and to create a network of regional medical libraries. The 1982 Cooper-Matheson report encouraged further action; NLM issued IAIMS contracts to four academic medical centers just before Lindberg's arrival. Under Lindberg and Richard T. West M.L.S., the NLM IAIMS Program Officer, IAIMS initiatives expanded and evolved.

The IAIMS calls for applications encouraged institutions to comprehensively and strategically plan how to interconnect people and information in clinical facilities, the medical library, research laboratories, and the educational arena. The goal was to address critical communication and information needs. The integration that IAIMS fostered was both physical (via networks) and intellectual (via computer applications providing new functionality). The IAIMS projects taught administrators, teachers, researchers, and students that informatics as a discipline had the potential to augment and improve their work. The lack of appreciation for informaticians on academic faculties dissipated, and institutions began to seek additional faculty trained in the field. The medical centers that received IAIMS grants during Dr. Lindberg's tenure at NLM became national leaders in informatics. They were widely emulated at other sites. Thus, the NLM IAIMS projects advanced academic institution's informatics infrastructures in profound ways, far beyond the set of IAIMS-funded sites.

Before the NLM began to issue research-oriented T15 training grants in 1984, a small number of institutions had begun to offer one-of-a-kind approaches to training individuals interested in informatics careers - via ad-hoc interdisciplinary degrees or custom apprenticeships. Greenes, Florance, and Miller describe how NLM established a uniform foundation for ongoing growth in the field in *Don Lindberg's influence on future generations: the U.S. National Library of Medicine's biomedical informatics research training programs* [4]. By 2017, shortly after Don Lindberg's retirement as NLM Director, 24 universities/institutions had received T15 training grants, and more than 1000 future members of the field had received NLM-sponsored training. Many of them later became leaders in the field at local and national levels.

Moreover, the NLM training grants promoted crucial interactions among new entrants into the field. The annual grant-related training meetings established a camaraderie among trainees and introduced them to senior faculty leaders from other institutions. The meetings acquainted trainees with NLM staff and showcased NLM programs as potential

means of future support. The training meetings increased awareness of the national scope of informatics activities.

By the early 1990s, interest in biomedical informatics careers had grown substantially, and extended far beyond sites having IAIMS or T15 training grants. Yet no national-level mechanisms existed to introduce uninitiated administrators, faculty, and librarians to the field. Lindberg strongly believed in using outreach programs to promote the adoption of NLM's initiatives. As James J. Cimino M.D. describes in *The biomedical informatics short course at Woods Hole/Georgia: training to support institutional change,* NLM developed a series of week-long informatics short courses [5]. These intensive courses were offered at Woods Hole, Massachusetts and, subsequently, at Augusta University in Georgia with a goal of training potential informatics change agents. Participants had to apply to be selected to attend. NLM paid for attendees' tuition, room, and board. Like the T15 training grant meetings, the short courses facilitated long-lasting collaborations among participants. Subsequently, many colleges and universities developed informatics course offerings patterned after the NLM short courses - including AMIA's 10x10 courses.

Before Lindberg became Director of the NLM, an individual entering the new academic discipline of biomedical informatics had few foreseeable options for obtaining ongoing long-term financial support. In *NLM's sponsorship of research in biomedical informatics (1985-2016)*, Kuo and Ohno-Machado review NLM's extramural R01 grant sponsorship during Lindberg's tenure [6]. Over three decades, NLM research grants evolved to support the field as it transitioned from a clinical informatics focus to add support for research in translational bioinformatics. The NLM Extramural Programs' annual budget kept pace with the growing number of individuals entering the field. It grew from $7.5 million in 1983 to $42 million in 2015. In addition, following NLM's lead, other NIH institutes began to sponsor informatics research and development projects.

Collectively, NLM's institutional IAIMS programs, T15 training grants, informatics short courses, and extramural research support created a vital infrastructure that supported the future growth of the field.

3. Examples of How the New NLM Information Infrastructure Enhanced Research and Clinical Care

During Lindberg's tenure, the NLM developed critical international information resources and novel informatics methods to access them. As Mo and Denny indicate in *The U.S. National Library of Medicine's impact on precision and genomic medicine*, Dr. Lindberg realized that the key to transforming biomedical research and clinical practice was creation of cross-indexed, interconnected databases with advanced access tools [7]. The tools were made publicly available at no cost to users.

In 2021, clinicians access NLM bibliographic, toxicology, public health, and genomic databases (among others) to diagnose and treat patients' disorders. Advanced cancer centers use NLM databases to develop and implement genetically targeted cancer therapies. The NLM's resources played key roles in addressing the COVID-19 epidemic

of 2019-2021. Such capabilities were barely imaginable in 1984. As a result, the NLM fundamentally changed the scope of available problem-solving approaches for biomedical researchers and clinicians and created new resources that could be mustered to address evolving problems. These enabled advances in genomic and personalized medicine.

McDonald and Humphreys, in *The U.S. National Library of Medicine and standards for electronic health records: one thing led to another*, explain how NLM evolved from an early position of eschewing ownership of non-bibliographic standards, to becoming the major U.S. Government maintainer and disseminator of healthcare-related standards [8]. These include resources developed during the UMLS project (see below) and others: LOINC, SNOMED, RxNorm, Structured Product Labels, and the DailyMed drug information distribution system. McDonald and Humphreys illustrate how the NLM's standards efforts enabled development of health information exchanges (HIEs), among many other important applications. An HIE creates a virtual patient record system - enabling clinicians at one of many sites where a patient has been seen to view an integrated composite patient record drawing data from all sites. It is only by mapping disparate data at each participating HIE site to NLM-sponsored standards that a monolithic, integrated patient view becomes possible.

4. How NLM Created an Information Infrastructure that Enhanced Progress in the Field

Four key NLM projects provided the foundation for the above-mentioned advances in clinical care and research. Humphreys and Tuttle describe the first of these in *Something new and different: the Unified Medical Language System* [9]. Masys and Benson in *Don Lindberg and the creation of the National Center for Biotechnology Information* document the second critical development (NCBI), which has had world-wide impact in promoting "omics" research.[10] The third development, the High-Performance Computing and Communications (HPCC) project, is described by Ackerman, Howe and Masys in *Don Lindberg, high performance computing and communications, and telemedicine* [11]. Finally, Ackerman, in *The Visible Human project* [12], details development of a resource that had implications well beyond anatomy representation.

The UMLS project began by enlisting university-based academic informatics teams into one of the earliest large-scale collaborations in the field. Key participants on the highly talented NLM project team included Lindberg, Harold M. Schoolman M.D., Betsy Humphreys M.L.S., Lawrence C. Kingsland Ph.D., Peri L. Schuyler M.L.S., Alexa T. McCray Ph.D., Daniel R. Masys M.D., and William T. Hole M.D. An initial round of individual demonstration projects gave way to coordinated efforts to build and maintain the main component of the project, the UMLS Metathesaurus. Lindberg envisioned it as enabling "the retrieval and integration of information from disparate electronic sources, e.g., patient records, biomedical literature, knowledge bases" [9].

Despite the talents of the assembled UMLS team, Lindberg realized that the NLM did not have the expertise or personnel required to build and maintain a single source "official" vocabulary for biomedicine which could support all aspects of clinical practice

and basic biomedical research. Instead, NLM adopted the approach of interconnecting frequently-used, well-organized and well-maintained vocabulary systems from both internal NLM sources (e.g., Medical Subject Headings - MeSH, and TOXLINE) and external sources (e.g., the International Classifications of Diseases, SNOMED, Current Procedural and Terminology, the Diagnostic and Statistical Manual of Mental Disorders, etc.).

The NLM engaged the services of Lexical Technology Inc. to carry out advanced processing of the raw component databases. The goal was to identify unique intellectual concepts no matter how the concepts' names varied across each UMLS source vocabulary. The Metathesaurus then designated a canonical name for each concept, and assigned a unique identifier that would not change even if the canonical name evolved. In turn, the project linked each canonical concept term to synonyms and lexical variants and maintained mappings back to the source vocabularies. The NLM subsequently "decided to create a separate UMLS Semantic Network, consisting of high-level Semantic Types or categories, e.g., Medical Device, Anatomic Abnormality, and the sensible relationships among them" [9].

The original Methathesaurus content included 64,000 concepts and 200,000 concept name variants. Methathesaurus content expanded 70-fold in size from 1990 to 2021. Applied UMLS projects world-wide number in the hundreds to thousands and range from supporting electronic health record systems to natural language processing applications, cataloging contents of medical school curricula and patient safety reports, linking patient charts to bibliographic references, and extracting health-related information from social media - among many others. Mo and Denny emphasize the significant impact of the UMLS in today's clinical practice environment and in biomedical research [7].

The NCBI grew out of a 1986 NLM Long-Range Plan visioning session whose charge was to improve the retrieval of factual information from databases. Three current and future Nobel laureates were in attendance. They indicated to Lindberg that current methods of accessing relevant databases in molecular biology and genetics research amounted to a modern Tower of Babel. Each database had a unique organization, a unique terminology, and unique access methods.

"The incompatibility of these closely related scientific resources thwarted a researcher's ability to use similarities and insights from one database to explain findings recorded in another and contrasted with the scientific literature where a single experiment might produce data that was then included in several disparate databases" [10]. The 1987 NLM Long Range Plan included the recommendation: "Immediately establish an intramural and extramural program for biotechnology information. The intramural component should be a National Center for Biotechnology Information, to serve both as a repository and distribution center for the growing body of knowledge and as a laboratory for developing new information analysis and communications tools essential to continued advancement in this field" [10,15].

Lindberg assembled a team that included Dan Masys M.D., Dennis Benson Ph.D., and NLM Deputy Director Kent Smith. Their preparatory work culminated with legislation authorizing creation of the NCBI in November, 1988. David Lipman M.D. was hired as NCBI Director in 1989. The legislative charge given to NCBI included: develop automated systems to store, retrieve, and analyze information related to

molecular biology, biochemistry, and genetics; determine how to represent and manipulate knowledge about biologically important molecules; enable biotechnology researchers to access the aforementioned systems and information; and coordinate collection of biotechnology information internationally [10]. The rest, as the saying goes, is history.

"For 28 years, until retiring in 2017, Lipman and his fellow NCBI leaders translated NLM's interest in advancing molecular science into tangible and widely used resources and tools for researchers worldwide. By all measures, the organization has exceeded the goals originally envisioned by Don Lindberg and the Long-Range planners, and its services have become woven into the fabric of 21st century science, continuing to catalyze biomedical research on a global scale" [10]. The PubMed interface developed by NCBI integrates and cross-references, among other things, access to NLM's bibliographic databases, OMIM, GenBank, dbSNP, and ClinVar, and MedlinePlus consumer-oriented health information. MedlinePlus' components include *Genetics* reference materials, general *Health Topics*, information on *Drugs & Supplements*, and information about *Medical Tests*. Again, Lindberg's schema of integrating, cross-linking, and providing new ways to access biomedical information paid significant dividends.

The HPCC project followed the theme of uniting resources on a much grander national scale. Ackerman, Howe, and Masys note that: "U.S. Government support for advanced computing in the 1950s and 1960s slackened in the 1970s" [11]. In contrast, the High Performance Computing Act, sponsored by Senator Al Gore, became law in 1986, with the goal of learning how to enhance computer network speeds, increase connectivity on a national level, and improve access to supercomputing centers. In 1991, the President's Office of Science and Technology Policy launched the HPCC program, and Don Lindberg was named Director of its National Coordination Office, concurrent with his ongoing position as NLM Director. Among its health-related projects, HPCC advanced "biomedical imaging, molecular biology, and molecular dynamics, and included NLM's Visible Human Project … and digital libraries" [11].

Ackerman tells the story of the Visible Human Project from his perspective as its prime mover [12]. His early focus at NLM was microcomputer-based education. After discussions with faculty members at the University of Washington about the shortcomings that medical students experience during cadaver dissections, Ackerman posed the question, "Would focusing on anatomy provide the example that would get medical schools to adopt interactive technologies?" [12].

Dan Masys, M.D., as then-Director of NLM's Lister Hill National Center for Biomedical Communication, suggested NLM should organize a workshop "to explore what a three-dimensional digital data set of human cadaver anatomy images might be used for" [12]. In writing the report of that workshop, Masys gave it the name, "Visible Human Project," which Lindberg then suggested to Ackerman. Lindberg agreed that it should include images from male and female cadavers.

The NLM's request for proposals to carry out the project specified that CT scan, MRI, and anatomical cross-sectional images should be aligned and cross-correlated. The project was awarded to Drs. David Whitlock and Victor Spitzer at the University of Colorado in Denver. The total project cost was $1,400,000, and the resultant image dataset size was 40 gigabytes. Ackerman concludes: "The Visible Human Project was a

complete success. It was used in high school, college, and medical school teaching; imaging algorithm development, testing, and comparison; physiological and radiation modeling; art; and digital network testing" [12].

5. Conclusion

This summary has described the wide variety of informatics-related contributions of the NLM and Dr. Donald A. B. Lindberg over a period of 31 years - coalescing to produce an impact on health and biomedicine that continues to this day. The chapter also emphasizes the transformative nature of those contributions, occurring in parallel and synergy with other remarkable changes that include the technological evolution in computers and communication, cultural changes in academic medicine and the health professions, and a new integration of biomedical science with both clinical care and population health.

Much of what observers, clinicians, public health workers, and biomedical scientists now take for granted can be attributed at least in part to the innovations engendered by the NLM, either through its intramural programs or its extramural support of informatics-related research and education.

Furthermore, the contributions have touched the global community by offering free access to the biomedical and clinical literature and to a variety of databases that play key roles in care, prevention, and research. The NLM has supported innovative projects that have created new methodologies that, in turn, have been generalized not only beyond a specific motivating project - but often beyond the biomedical and clinical sciences to other diverse areas of application. Having surveyed the accomplishments and transformative impacts documented herein, the editors and chapter authors stand in awe of what Dr. Lindberg and the NLM accomplished. Humankind owes a great debt to both the man and to the organization he led.

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A Scientific Mind Embraces Medicine: Donald Lindberg's Education and Early Career

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Abstract. As a young pathologist, Donald A. B. Lindberg, M.D., tirelessly sought scientific solutions to clinical and research problems. Directing several clinical laboratories at the University of Missouri in Columbia, Dr. Lindberg developed the world's first computerized laboratory information system, speeding analysis and reporting. He directed his team in building computer systems to help clinicians retrieve medical knowledge, enable patients to find information about personal or family health issues, and provide expert automated assistance to physicians in reaching differential diagnoses outside their specialties. Developing superior functionalities with the limited information technologies of the time, Dr. Lindberg's pioneering work in Columbia foreshadowed his subsequent inspired leadership as Director of the United States National Library of Medicine.

Keywords. Donald A.B. Lindberg, Laboratory Information Systems, Computers in Medicine, Regional Medical Program, University of Missouri-Columbia, Artificial Intelligence, Knowledge Based Systems, CONSIDER, AI/RHEUM, AI/COAG.

1. Introduction

Donald A.B. Lindberg, M.D., enjoyed a long and distinguished life of great accomplishment, continually pushing the boundaries of medical knowledge, emerging technologies, and scientific possibilities. His education and early experiences show a curious mind seeking answers, an unflinching approach to confronting challenges, and an impressive ability to devise practical solutions to complex problems. This chapter describes aspects of Dr. Lindberg's professional development that helped lay the foundations for his visionary and innovative leadership as Director of the United States National Library of Medicine.

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2. Brilliant Student Meets Gifted Teachers

Donald Allan Bror Lindberg was born and raised in Brooklyn, New York. He graduated in 1950 from an excellent secondary school, Polytechnic Preparatory Country Day School on Dycker Heights. He maintained a lifelong connection with the school and would note later, "I always say – bar none – those were the most important four years of education for me" [1,p.3]. After graduating from Poly Prep and carefully researching options, Lindberg selected Amherst College for the next phase of his education. Don arrived as an English major but fell in love with biology when he met Dr. Oscar Schotté.

Dr. Schotté introduced him to experimental embryology, which Lindberg found fascinating. An Amherst honors program allowed concentration on lab experiments in the third and fourth years. The budding biologist said "We had our own labs, we had our own animals, we had our own histologists – although I could do histology" [1,p.3]. Some of his experiments with Dr. Schotté are reported in FASEB (Federation of American Societies for Experimental Biology) and in other publications [2]. Donald Lindberg graduated *magna cum laude* from Amherst in 1954.

The deep interest in biology led him to discuss with Dr. Schotté a doctoral program at the Rockefeller Institute, but Lindberg decided to go to medical school at the Columbia University College of Physicians and Surgeons. He would say later, "It's thrilling and it's tedious, in alternating combinations. It's a sort of a grind that's committed to large amounts of memory work, which is really almost antithetical to experimental science. But, it has its appeal. Every once in a while you get to see some patients" [1,p.4].

Donald Lindberg graduated from the College of Physicians and Surgeons (P & S) in 1958. He had been attracted to every single medical specialty he was exposed to, one by one: internal medicine, general surgery, obstetrics, psychiatry, pediatrics, and others. He had been offered an internship in internal medicine at the College by Robert Loeb, a giant in the field. But in the end, he said, "I decided that pathology actually had answers" [1,p.4].

3. Life-saving Discovery by a Pathology Intern

One set of answers was particularly important. About six months into the beginning of his pathology internship, the freshly graduated Dr. Lindberg was working on analyzing causes of death at Presbyterian Hospital. Deaths from open heart surgery, then in its infancy, were quite frequent. Lindberg, working with autopsy tissues, noticed something no one had spotted before. He brought these microscopic sections to his chiefs, asking "What is this? This is a funny-looking thing." He was essentially told "Forget about it, it's nothing" [1,p.5]. But he got curious, learned about polarizing microscopes and special stains, and concluded the people were dying from the embolization of silicone particles used to reduce foaming in the oxygenators: "And so their arteries of the brain and of the heart were so choked with physical emboli that you couldn't oxygenate the tissues, and they died" [1,p.5,3].

It was late fall, halfway through the academic year. He went to the surgeons, told them what was happening, and was put off because they were too busy until perhaps

May. Dr. Lindberg, halfway through his first year of training in pathology, notes that he "went to the Chairman of Path, a very tough character, Harry P. Smith, from Iowa… [Dr. Smith] said, 'Well, show me what you're talking about'" [1,p.5]. Lindberg did so. Dr. Smith said, "Okay, here's what you're going to do: get another dozen microscopes, set them up in the pathology library, … I'm going to invite the Department of Surgery, and I'm starting out with the senior faculty, to have a little meeting with us" [1,p.5].

The meeting took place, and speaking bluntly about a proposed follow-up meeting, H.P. Smith told the surgeons, "Either we have the meeting and you guys start doing what Lindberg wants you to do, or I'm going to call the district attorney and shut you down" [1,p.5]. Dr. Lindberg notes, "So it actually got somewhat confrontational. We did alter the surgical technique. I did do experiments with the surgeons. We did publish them in peer review journals, and everybody agreed" [1,p.5,3]. This was a remarkable accomplishment for a newly-fledged M.D. who was a pathologist-in-training halfway through his first year of residency. It is characteristic of Don Lindberg's focus and creativity in coping with an unknown tough problem, his sheer persistence and force of will, and his strong follow-through in the face of significant obstacles.

4. Move to University of Missouri-Columbia School of Medicine

After two years in his Pathology Residency at Columbia P & S, Dr. Lindberg transferred to the Department of Pathology at the University of Missouri-Columbia School of Medicine. Driving around Columbia on an interview trip, Lindberg had spotted two little boys in cutoffs with bikes and fishing poles and thought "My God! What a wonderful town it must be for a kid to grow up in" [1,p.6]. He accepted the offer to move, and he and his wife Mary raised three sons in Columbia.

The Dean of the Missouri medical school was Dr. Vernon Wilson, in his first deanship. Dr. Lindberg later said "He was just an incredibly wonderful person to work with" [1,p.7]. Under Dr. Wilson, the school seemed to be moving forward quite rapidly.

As a junior faculty member, Dr. Lindberg was running several clinical laboratories and teaching pathology. He had brought with him from P & S an NIH research grant, one of only a few at Missouri at that time. The grant combined pathology and infectious disease, investigating a Gram-negative pneumonia into which he had taken an interest. Lindberg notes, "NIH liked it enough that they gave me the money, and I brought the money to Missouri and started up a research laboratory" [1,p.7].

5. Microbes in Orbit

The pathologists were making ward rounds every day to see the patients with the interesting cultures. Dr. Lindberg, now a dedicated teacher in his own right, invited the pathology residents along to see and learn. Soon the internal medicine residents were coming along too. With an infected patient, and an organism cultured from the site, the immediate question is "What antibiotic should I use?" Lindberg started looking into means of assessing the sensitivity of microbes to both antibiotics and antiseptics. The

highly-qualified young technician who was running the research lab with him was married to a gentleman named Garst Reese, a second-year physics major at Missouri who had worked for Texas Instruments for several years. Dr. Lindberg and Mr. Reese spoke about the problem, which interested both of them. Lindberg continues, "Anyway, we invented a machine. We convinced ourselves that we could get these bugs, these microbes, growing in a liquid culture, and then use Rayleigh's law to measure scatter, to get a sense of how many there were. We had a few little technical problems, like we'd have to keep them suspended, and we'd have to move them around and shine a light through it consistently, and have good photometrics" [1,p.8]. They thought in 3 or 4 months they could design this machine. It took 3 or 4 years [4]. Ultimately, NASA sent their device into earth orbit in a satellite doing environmental monitoring.

6. World's First Computerized Laboratory Information System

Part of this experience led Dr. Lindberg to mathematical modeling of bacterial growth patterns. Primary tasks included logging the output of the experimental device, then running a series of equations that modeled what was going on in the growth process. It became clear that something like a computer was needed. The university did have a computer center, with a Burroughs 205 paper tape machine. A card reader became available later. Lindberg concurrently oversaw the operation of several labs, such as microbiology and medical chemistry. He would later say, "So anyway, half the day I was trying to do this mathematical modeling with this old 205 and a big string of equations. The other half of the day, I was trying to get the results out of the lab… So I developed a system of a presorting, where the message would be broken up into pieces, and each of those pieces would be in a pre-punched card, and to get a message out, you'd assemble a set of these cards, and then run it through a reader. That would drive a teletype that would print a message on the ward. And then, courtesy of the university, I was assigned 15 minutes a day of computer time, which was, of course, a quarter to midnight [until] midnight" [1,p.9].

He also had an IBM 1620 by this time. That machine could read cards. He could produce a summary. Lindberg says, "I was learning more neat stuff, like the mathematics, and I was getting an improvement in the lab, and the reports were getting out not only the same day, they were getting out within minutes. Besides making the lab reports available more quickly, we had a record of them, so we could start doing some quality control, which we did right away" [1,p.10]. This was the first computerized laboratory information system in the world. It was clear to Dr. Lindberg that he needed his own computer center to do this and other systems to his own standards. Dean Wilson said, "Well, why don't you start one?" [1,p.14]. They put in an IBM 1410 using some of Lindberg's research grant funds. The university itself only had a 1401, so the two parties negotiated a certain amount of time per week for the university to use the 1410 to print thousands and thousands of salary checks.

7. Regional Medical Program

Dr. Lindberg, by then doing some consulting with IBM and similar companies, saw an important missing link: contact between the university and industry, the research sides of the companies. He said he wanted his own work both to become more practical, and to benefit from more collaboration with industry. It was 1965, and the federally funded Regional Medical Programs were beginning. The genesis of these programs was President Lyndon B. Johnson's respect for Dr. Michael DeBakey, who had agreed to head a group that produced an influential report on heart disease, cancer, and stroke. Both the Regional Medical Programs and the Medical Library Assistance Act stemmed from that work.

The Regional Medical Program assumed that individual regions of the US would know best what they needed and could design their own goal-oriented projects. Program funding enabled people in a given region to conduct a needs analysis and plan corresponding projects. Lindberg said, "It had an underlying theme, from lab to bedside, so to speak. In other words, get the new discoveries out there and in use. Some of the new discoveries in those days, for instance, were myocardial infarction research and surgical intensive care units" [1,p.13].

Dean Vernon Wilson, later Vice-President of the University, was a key person in planning for regional medical programs and in advising the Washington side on writing the legislation and the appropriations correctly for the intended purposes. The net result was that Missouri received one of the first four planning grants for regional medical programs and was the first or second one actually funded. Lindberg reported, "So that solved the problem of resources and a reason to work with the engineers and the others. That was a very exciting period for me" [1,p.13]. The Missouri Regional Medical Program involved multiple individual projects; several are discussed below.

7.1. Computer Fact Bank

One project was the Computer Fact Bank, directed by Lawrence C. Kingsland, Jr., M.D. [5]. The Fact Bank was an open-ended collection of biomedical information equivalent to several hundred thousand text pages. It contained appropriate current facts and definitions, basic science, and clinical and research information. The majority of the collection was journal, monograph, and textbook material on 16mm microfilm in cartridges and on microfiche. About 2,000 pages were in machine-readable form on magnetic tape. This information was loaded into a device called a Selectriever built by the Mosler Safe Company. Any one of these pages, whether on microfilm, microfiche, or magnetic tape, could be displayed within 30 seconds on viewing terminals from which copies of desired pages could be created if needed. Organization for retrieval was done using a Depth Index similar to a Thesaurus. The Depth Index was based on NLM's MEDLARS Subject Heading Authority Lists merged with the College of American Pathologists' *Systematized Nomenclature of Pathology* and the Indexes and Tables of Contents of several representative important textbooks and monographs, retaining important semantic and hierarchical relationships.

7.2. Remote Computer-Based EKG Interpretation

Another Regional Medical Program project involved portable, wheeled EKG carts that recorded EKGs to reel-to-reel magnetic tape. Acoustic couplers built into the carts were used to send EKGs over telephone lines from remote locations to cardiologists for interpretation or to a new computerized system developed in Washington, D.C. by Dr. Cesar Caceres of the Public Health Service. Dr. Caceres had won awards for creating the country's first functioning computer-EKG interpretive system. He later joined George Washington University, where he was Professor of Clinical Engineering.

For most users in the late 1960s, remote access consisted of telephone lines, modems, and acoustic couplers connecting a terminal with a computer in another location. The ARPANET (Advanced Research Projects Agency Network) project began in 1966. It became the first wide-area packet-switching network with distributed control. It was also one of the earliest networks to implement the TCP/IP protocol suite. This suite allowed one network to hand off data packets to another, then another. Both technologies were critical to what we now know as the Internet. ARPANET software developers wrote applications and protocols such as Telnet and file transfer protocol (FTP). In 1971, BBN's Ray Tomlinson wrote the first email program. The ARPANET community took to it immediately. The network was declared operational in 1975 when control passed to the Defense Communications Agency [6].

7.3. Audio Message Center

Few households had access to a computer, but even in rural America, many had telephones. Always considering more ways to bring medical information to those with limited access to it, Donald Lindberg thought of those phones. He reasoned that offering telephone call-in to an Audio Message Center could provide an inexpensive means of playing brief audio messages on medical topics that could be helpful for patients, caregivers, and other information seekers. The low-tech but impressively effective solution he and colleague Mr. Guy Morrison came up with was a common automotive accessory of the time: an 8-track stereo cartridge tape player.

If an 8-track stereo cartridge could hold eight songs, each with a left and a right channel, then there were 16 addressable audio subchannels. Adding a little electronic surgery on the stereo playback head assembly, a few relays and other switching gadgetry, a small power supply, and a rack mountable chassis resulted in an inexpensive and quite reliable means of message playback. In quantities of 50, the tape players (bought caseless because the case would have been discarded anyway to get access to the mechanism) cost $34 each. With 12 six-foot cabinet racks, each holding 10 cartridge tape chassis units with 16 messages per unit, the total capacity of a fully built-out system was 1,920 messages. In time, colleague Mr. Roland Ellis, who had a mellifluous voice that would have done a radio announcer proud, had recorded 1,200 messages varying in duration from 2–16 minutes. To distribute the load, these were spread across all 12 cabinet racks at 100 messages per cabinet. They were available 24 hours a day, 7 days a week, without any operator intervention.

8. Knowledge-Based Systems

8.1. Knowledge-Based Systems: CONSIDER

The Audio Message Center and a telephone brought useful information directly to the medical consumer. Perhaps a computer could be helpful in bringing another form of useful information to the healthcare professional, such as a physician or a medical student. The CONSIDER programs developed by Dr. Lindberg and the staff of the University of Missouri Medical Center Computer Program accepted a set of signs, symptoms, or medical findings as input. They produced a differential diagnosis: a list one should *consider*, which might include both common, reasonable diagnoses and those of much more rare, exotic diseases or conditions. In a simple example, the student could enter two common findings, "leukocytosis" and "abdominal pain". The CONSIDER program would then respond with 29 possibilities. At the top of the list would be the two most common candidates: "pyelonephritis" and "peritonitis". The remaining 27 would include less likely, but still possible, diagnoses such as "acute intermittent porphyria" and "iliac abscess". The original CONSIDER programs were run on the IBM 1410 computer with printer and punch card outputs. Later versions on the IBM 360/50 used CDC or IBM 2260 cathode ray tube terminals for output. The organized knowledge used by CONSIDER began with the magnetic tape version of *Current Medical Terminology* (*CMT*) by the American Medical Association, slightly rearranged and with a few modifications. Synonym tables were created to relate CMT diagnoses with those *Standard Nomenclature of Diseases and Operations* diagnoses which were used at the University of Missouri Medical Center (UMMC). It was then possible to sort the CMT tape in order of the frequency with which these diagnoses had been made at the UMMC. This way, the diseases most common at this institution would be listed first. CONSIDER was one of the first such systems in the world [7].

8.2. SUMEX-AIM and the Rutgers Research Resource on Computers in Biomedicine

In 1969, Dr. Lindberg was asked by NIH to serve on a study section evaluating grant proposals in Computer Research and Biomathematics. He participated in this group from 1969 to 1971, meeting many other pioneers in what was to become biomedical and healthcare informatics. Among them was Dr. Edward Feigenbaum of Stanford University, who became a lifelong friend. Dr. Lindberg notes, "… Ed was, even then, a real expert in artificial intelligence, and a colleague of Joshua Lederberg and Carl Djerassi and all those guys. So we kind of fell in together and started doing some projects together. That got me started in the artificial intelligence business" [1,p.15]. Dr. Lederberg was later to ask Dr. Lindberg to chair the National Advisory Committee of the NIH-sponsored Stanford Experimental Artificial Intelligence in Medicine (SUMEX-AIM) project. The Committee evaluated proposals from other universities to use the computing facilities of SUMEX-AIM. Lindberg chaired this group from 1975 to 1984, during which time the existing Rutgers Research Resource on Computers in Biomedicine became the second major NIH-supported program to join with SUMEX-AIM in providing online computing resources for their work on artificial intelligence in

medicine. These two DECsystem-20 computer complexes successfully supported university AIM research across the country for over a decade.

Dr. Lindberg at Missouri and Dr. Casimir Kulikowski of the Rutgers Research Resource on Computers in Biomedicine became close collaborators.

8.3. Knowledge-Based Systems: AI/RHEUM

In his travels to Stanford related to SUMEX-AIM, Donald Lindberg had met Dr. Gordon Sharp, a professor of medicine and an internationally known expert in rheumatology. Dr. Sharp subsequently was recruited to the University of Missouri to set up a Division of Immunology and Rheumatology at the School of Medicine. Deciding to explore a collaboration, Drs. Lindberg and Sharp in 1978 started a series of seminars hosted alternately by the rheumatologists and by Lindberg's computer group. The researchable problem that emerged from these seminars was the development of an artificial intelligence program that, when presented with patient findings, could suggest diagnoses in rheumatology and musculoskeletal diseases.

The system came to be called AI/RHEUM [8]. Its intended users would be physicians not having specialty training in rheumatology. Three teams were involved: Lindberg's Information Science Group and Sharp's Division of Immunology and Rheumatology at Missouri, and Kulikowski's group of computer scientists at the Rutgers Research Resource, including Sholom Weiss, who had recently completed his doctoral dissertation on the novel causal-associational network (CASNET) model of diseases. Kulikowski and Weiss had generalized CASNET into a framework called EXPERT for representing clinical expertise for the diagnosis and treatment of medical specialty diseases. EXPERT proved to be a critically important software package for helping acquire and represent the knowledge used in AI/RHEUM and subsequently in many other expert consultation programs [8]. The name was well chosen, in that EXPERT was a complex tool (or shell) for building what were coming to be called expert systems [9].

Using the EXPERT shell, the flow of reasoning for AI/RHEUM moved from its 877 potential patient findings through 467 intermediate hypotheses to eventually reach one or more of 26 potential disease conclusions. The system did not require observations for all 877 possible findings; it reasoned with whatever information was given. It notified the user if the information was insufficient to trigger any of the disease conclusions [10].

Disease criteria tables provided an information-dense means of organizing information that was both human-readable and readily translated into rules with which the EXPERT inference engine could reason. This form of knowledge representation, at the heart of AI/RHEUM, was unusual among the few medical expert systems of its time. Patient findings such as signs, symptoms, laboratory test results, or radiographic observations could be designated as Major Decision Elements or Minor Decision Elements. Other findings could be designated as Required, or as Exclusionary. Clinical combinations of those findings could lead the system to conclude that the disease in this case was Definite, Probable, or Possible [11].

Validation has been critical for clinical informatics systems under development. From its outset, AI/RHEUM was challenged using real clinical cases. As of 1986, AI/RHEUM had been tested with more than 500 carefully studied cases in three series

[10]. Cases in the first evaluation series were selected because they carried discharge diagnoses in the system's knowledge base. AI/RHEUM diagnosed 360/384 cases correctly (94%). The second series consisted of all but one of the cases serially admitted to the Arthritis Unit at the University of Missouri in Columbia during two 60-day periods (one chart had been lost). For those 74 cases, the researchers found that 63 carried diagnoses in the AI/RHEUM knowledge base (85%). All 63 were correctly diagnosed. Of the 11 cases carrying diagnoses not in the knowledge base, AI/RHEUM correctly refused to make a conclusion on five. For the remaining six cases, the program was misled by features of diseases it knew, misdiagnosing all of them. The final AI/RHEUM evaluation series came from clinical rheumatologists at Keio University in Japan. They sent 59 difficult-to-diagnose cases involving patients with connective tissue diseases. AI/RHEUM diagnosed 54/59 cases correctly (92%), 3/59 cases partially correctly (5%), and 2/59 cases incorrectly (3%). Each of the cases for which AI/RHEUM was judged partially correct carried either three or four diagnoses from the Japanese rheumatologists. For each of those cases, AI/RHEUM had included all but one of those three or four diagnoses in its differential [10].

8.4. Knowledge-Based Systems: AI/COAG

After the AI/RHEUM system development was well under way, Dr. Lindberg in 1980 began a collaboration with another Missouri colleague, Dr. Lamont Gaston. Dr. Gaston was an expert in human hemostasis – the diagnosis and treatment of blood clotting disorders. Though clinical hemostasis problems are somewhat uncommon, they are often serious and require urgent expert attention [12]. Experts such as Dr. Gaston were both rare and sparsely distributed; most were found in large referral centers. Lindberg and colleagues hypothesized that a knowledge-based system, later called AI/COAG, could be modeled after human experts. Such a system could provide expert-level advice in locations lacking human experts. The AI/COAG system could also provide useful educational functionality for medical students, resident physicians, hematology fellows, and allied health personnel.

The original version of AI/COAG could interpret a constellation of six laboratory coagulation screening tests and evaluate a clinical hemostasis history. The six coagulation screening tests included the platelet count, Mielke-template bleeding time, prothrombin time, activated partial thromboplastin time, thrombin time, and urea clot solubility test. While the laboratory subsystem returned a detailed analysis and interpretation of the test results, AI/COAG was unusual in that it offered expanded information on specific aspects of the interpretation in the form of "Tell-Me-More" (TMM) items. It also provided access to the literature sources underlying the knowledge base, stored in the form of "Tell-Me-Reference" (TMR) items. Each TMM or TMR could have other TMM or TMR items embedded within it, for further detail [13].

The AI/COAG model viewed laboratory test results for each patient as a pattern. The six screening test results were viewed as a six-digit trinary number in which results are normal, decreased, or elevated. Examined in this manner, 729 six-digit patterns (3^6) were possible. Only 324 of these were medically plausible. The full AI/COAG report for each patient's coagulation screening test results consisted of a Summary section

reporting the test results themselves, an Analysis section that identified abnormal test results, and an Interpretation section that contained the bulk of the computer-based consultation in the form of a differential diagnostic interpretation. Embedded TMM and TMR items were available for users who might want to invoke them.

To help provide maximum guidance to the non-expert user, a final printed paragraph following the interpretation emphasized the relative prevalence of the disease entities in the differential diagnosis.

The portion of the AI/COAG system dealing with laboratory tests was used to evaluate data from 315 cases. Forty-one patterns of laboratory results were seen, with just 18 patterns comprising 90% of the cases [13]. The system suspected a hemostatic defect in 46 of the 315 cases. These were studied at an outside laboratory. Relying only on the laboratory data, AI/COAG appropriately concluded that there was a defect of hemostasis requiring study in 76% of these cases [13].

The clinical history portion of the program was challenged to evaluate the history of 51 known patients with hemostatic defects attending the University of Missouri Medical Center. Of the 44 cases of hemophilia A or B, the system concluded that a definite hemostatic defect was present in 40 patients. For three additional patients, it concluded that a probable hemostatic defect was present. Note that from history alone, AI/COAG could conclude only that a defect was present (at the Definite, Probable, or Possible level). It did not attempt to make a specific diagnosis until laboratory test results were provided [12].

9. New Challenges Beckon

We have discussed only a few of the many interesting and productive projects undertaken during Don Lindberg's time at the University of Missouri. The work of Dr. Lindberg and his team there, applying science and multiple technologies to advance the knowledge and practice of medicine and biomedical research, might have continued for decades. He greatly enjoyed his work, and the Lindberg family loved their life in Columbia. Dr. Lindberg, however, had drawn the attention of academic and government leaders in many positions. He was urged by persons he respected to take his talents to a national and even a global stage. An important opportunity arose.

Don Lindberg left the University of Missouri in 1984 to become Director of the United States National Library of Medicine. He observed later, "NLM is great, a unique place…. [P]eople are there because they can do something they can't do anywhere else" [1,p.19]. Lindberg would remain in this post for 31 years, making progress in medical science ever more available to healthcare practitioners, scientists, and the public around the world. He retired from the Library in 2015, having been instrumental in furthering multiple significant advances detailed elsewhere in this volume.

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Donald A.B. Lindberg, Pioneer in Biomedical and Health Informatics: His Involvement in Creating Professional Organizations

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Abstract. Among the many contributions of Donald A.B. Lindberg was his work on behalf of a variety or professional organizations in the field of biomedical and health informatics. These began during his early days at the University of Missouri and continued throughout his 30 years at the National Library of Medicine. This chapter summarizes that work, which occurred both through his personal efforts and through the impact of the NLM under his leadership. Examples include his role in the development of organizations themselves (e.g., the International Medical Informatics Association, the American College of Medical Informatics, and the American Medical Informatics Association) and also his contributions to the professional scientific meetings that have advanced the field (e.g., the Symposium on Computer Applications in Medical Care, MEDINFO, and the AMIA Annual Symposium).

Keywords. Donald A.B. Lindberg, Medical Informatics, International Medical Informatics Association, American Medical Informatics Association, U.S. National Library of Medicine.

1. Introduction

Donald A.B. Lindberg M.D. was a pioneer in many fields, including biomedical and health informatics. Known especially for his role as Director of the National Library of Medicine (NLM), he was a great advocate and promoter of the informatics field. Throughout his career, he maintained key interests in both main themes and in details. Nevertheless, amid all his organizational activities, Lindberg remained a scientist:

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curious, open to new ideas, positively responsive to the unexpected, innovative, and creative.

In this chapter we focus on Dr. Lindberg's important contributions to the organizational development of biomedical and health informatics, which we simply call *informatics* hereafter for brevity. Note that he was based at the University of Missouri until, in 1984, when he became NLM director and moved from Columbia, Missouri to Bethesda, Maryland (where the NLM is located on the campus of the National Institutes of Health [NIH]). Dr. Lindberg served at NLM for a remarkable 31 years until his retirement in 2015. Throughout his career, both at Missouri and subsequently at NLM, he was actively involved with a wide variety of professional organizations and meetings related to the informatics field.

Although this chapter is not about his personal research work, we note that Lindberg always surrounded himself with a team of top researchers and superb staff members. That many had prolonged careers at NLM under Don's leadership demonstrates that he was highly professional, shaped a positive workplace environment, and exhibited heartfelt concerns for his coworkers. A few key references to Lindberg's varied work appear at the end of this chapter [1-5]; more appear in [6].

In this chapter we start by discussing how Lindberg's training and medical background brought him naturally to the field of informatics. We then note how his growing reputation as a scientist and leader in the field enabled him to play key roles in the development and evolution of several key organizations and meetings, many of which continue to define the field until today. These include both professional societies in the U.S. and the growth of an international community of professionals in the field. We then turn to how his leadership at the NLM itself has influenced the organization and growth of the field. Finally, since all chapter authors had close personal relationships with Don over many decades, we close with some personal observations about the man, his leadership, and his impact on people both professionally and personally.

2. Biomedical Background – Ideal for Contributions to the Field of Informatics

Lindberg received his Bachelor of Arts degree *magna cum laude* from Amherst College and his MD degree from the College of Physicians and Surgeons at Columbia University. While at Amherst, he studied experimental embryology and contributed to the literature on limb growth and regeneration. He received his postdoctoral training in anatomic and clinical pathology at Columbia-Presbyterian Medical Center in New York and began his career as a pathologist.

In 1963, he founded one of the first medical computer centers in the U.S. at the University of Missouri-Columbia, where he served on the medical faculty. Of course, Don first applied computers to his own field of pathology. He also was one of the early contributors to computer-assisted medical decision-making and education. He went on to garner many appointments and honorary doctorates at prestigious universities. Don published extensively in the fields of pathology as well as informatics, authoring several books, book chapters, and more than 200 articles and reports. He served as an editor and

editorial board member of nine journals, including *Methods of Information in Medicine* and the *Journal of the American Medical Informatics Association*. For additional details, please refer to [7].

> When Jan van Bemmel visited him at his home in Columbia Missouri in February 1983, Don proudly showed his recently purchased IBM personal computer, equipped with an Intel 8080 – now a collector's item. At that time, he was, in addition to being Professor of Pathology, also Professor of Information Science at the University of Missouri-Columbia.

3. Pioneering role in Medical and Health Informatics

In discussing Lindberg's pioneering role in informatics organizations, we first discuss his key contributions to the evolution of organized informatics in the U.S. This work extended over many years, beginning in Missouri but growing in importance after his move to the NLM. As we describe, his work to support the creation of organizations in the U.S., and the scientific meetings for which they are known, was key – and is reflected in the professional organizations that we see today. We then focus on his role in global organizations, where he became a key international figure as the field grew. These international activities include development of the principal international society for the informatics field, efforts to enhance the role of informatics in assuring quality and reliability of health information, and the evolution of a major peer-reviewed journal in the field.

3.1 AAMSI, SCAMC, ACMI and AMIA

To address Lindberg's impact in the U.S., we must begin by introducing briefly the early days of the development of American professional activities related to informatics. In 1977, Helmuth F. Orthner, Ph.D., and William Yamamoto, Ph.D., both at George Washington University (GW) in Washington, began hosting a local, U.S. District of Columbia area conference that they titled the Symposium on Computer Applications in Medical Care (SCAMC)[2]. Lindberg was a presenter at the initial meeting and a regular attendee in subsequent years. As interest in the meeting grew, Thomas Piemme, M.D., GW Medical School's Assistant Dean and Director of Continuing Medical Education, helped to secure funding for an expanded version of the meeting, and marketed it broadly both nationally and internationally. Following the success of the expanded meeting, Piemme legally incorporated SCAMC, and became the organization's Executive Director.

Piemme had first met Lindberg in 1966, at which time both had been appointed as Markle Scholars[3]. By 1982, when Don was at the University of Missouri and was

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[2] Information in this section derives in part from an interview recorded with Thomas Piemme, MD just days before his death in April, 2021.

[3] See https://www.nature.com/articles/163437c0 and https://www.markle.org/

chairing the NLM's grant review group (then known as the Biomedical Library Review Committee), he was already highly visible in the biomedical computing community. Accordingly, Piemme and the SCAMC Board of Directors recruited Lindberg as their first board member from outside the Washington, DC area. Only two years later, Don moved to the Washington area to assume his leadership role at NLM and continued to be highly involved with SCAMC oversight.

Shortly after Don's appointment to the SCAMC board, Piemme was elected to the Board of Directors of the American Association for Medical Systems and Informatics (AAMSI), where Don also was to serve on the Board in the mid-1980s. AAMSI was the major U.S. membership organization in the field and it held its own annual meeting every spring, typically on the West Coast to avoid direct conflicts with SCAMC.

Meanwhile, at the 1982 SCAMC meeting in Baltimore, Morris F. Collen, M.D. invited Lindberg, Piemme, Edward H. Shortliffe, M.D., Ph.D., and M. Scott Blois, M.D., Ph.D., to a private meeting in which he suggested creation of an American College of Medical Informatics (ACMI), to consist of nominated and elected Fellows. In 1985, the first 52 ACMI members were elected by 100 individuals who had been nominated to be founding fellows. ACMI was in turn incorporated and Scott Blois served as the first ACMI President, with Tom Piemme as Secretary/Treasurer. Piemme's GW office initially managed the operation of ACMI, as it did SCAMC.

By 1988, leaders of the major American informatics organizations (all of which involved Lindberg in their leadership) – AAMSI, SCAMC, and ACMI – deemed it illogical to maintain three separate corporations since their functions were complementary. The organizations had overlapping Boards of Directors, similar activities, and common members/attendees. Led by ACMI President Homer R. Warner M.D., Ph.D., and AAMSI President William W. Stead, M.D., their two organizations were fully supportive of discussions regarding merger. By contrast, SCAMC President Yamamoto, and some of the other original SCAMC Board members from Washington, initially opposed a merger despite the urging of many of the other board members, including Lindberg. This delayed progress temporarily. When Shortliffe succeeded Yamamoto as SCAMC President, plans to merge regained momentum.

The three boards agreed that it would be in the best interests of the new entity – to be called the American Medical Informatics Association (AMIA) – if they could identify a particularly respected individual to be the founding President of the organization. The three legacy organization presidents (Warner, Stead, and Shortliffe) were excluded from consideration by mutual agreement. Lindberg was the obvious choice. He was approached in late 1988 about becoming the founding President (board chair) of AMIA and agreed to serve. Of note, Don was appointed by the outgoing boards since the entity did not yet have a voting membership. He started to chair meetings of the interim board. This process is documented in an October 17, 1988 letter written by AAMSI President Stead to Lindberg. That letter identified Don as both President of AMIA and Director of the National Library of Medicine. In the letter, the AAMSI Board of Directors set forth conditions for AAMSI's merger into AMIA.

In 1988-89, Piemme arranged for AMIA to become incorporated as an organization headquartered in Washington, DC. While that initially created a shell corporation, the logistics of dissolving three corporations, and creating a new, non-profit, tax-exempt

501-(C)(3) organization required U.S. federal government approval. Funds from ACMI, SCAMC, and AAMSI could not be transferred to AMIA until the Internal Revenue Service approved AMIA's educational/charitable status.

There was broad agreement that the new organization should establish its own staff and space, which explains why AMIA opened offices in Bethesda, to be close to Don's workplace at NLM. It continues to be based in Bethesda today. AAMSI members all automatically became AMIA members. The College (ACMI) worked out a scheme whereby it would be part of AMIA but would be self-governed using rules adapted from its initial bylaws from 1984. Per the merger agreement forming AMIA, for its first five years AMIA continued to call its annual conferences SCAMC. Thereafter the meeting was called the AMIA Annual Symposium, which continues to this day. After AMIA was officially formed through the formal merger of AAMSI, SCAMC, and ACMI, and with Lindberg's leadership, it quickly grew as the principal society for informatics in the U.S.

The AMIA Board meeting of January 9, 1990 was led by President Lindberg. Other AMIA Board (BOD) members at that time, in addition to Lindberg, Warner, and Shortliffe, included Michael Ackerman, Ph.D.; G. Octo Barnett, M.D.; Morris F. Collen, M.D.; W. Edward Hammond, Ph.D. (Treasurer); Daniel K. Harris; Edward J. Hinman, M.D.; Frank M. Holden, M.D.; Pat Jacobs, R.N., M.N. (Secretary); Clement J. McDonald, M.D.; Helmuth Orthner, M.D.; and Judith Ozbolt, R.N. In attendance as guests were Joyce Mitchell, Ph.D. and Randolph A. Miller, M.D. – the respective Program Chairs of the forthcoming AMIA Spring and Fall AMIA/SCAMC meetings. These were the first national meetings held under the AMIA banner. At the January board meeting, the AMIA legal counsel noted that the official incorporation of AMIA as a legal entity would not be completed until later in 1990, due to the requirements of registering as a 501 (C) (3) tax exempt organization. Nevertheless, the Board had the authority to act as if incorporation was in place.

At subsequent 1990-1991 AMIA Board Meetings, under Lindberg's guidance, the following noteworthy events occurred: approval of annual ACMI retreats; creation of AMIA's Professional Specialty Groups (later called AMIA Working Groups); creation of the AMIA Executive Director position; creation and population of AMIA Standing and Ad Hoc Committees; and establishment of procedures for election of new AMIA Board members. The AMIA Board in August 1990 directed the Publications Committee Chair to pursue possible creation of AMIA's own new journal (which eventually became JAMIA). Based on a November 1991 report of the AMIA Publications Task Force, the AMIA Board of Directors voted that AMIA would own Copyright to all editorial material published in its future journal; that AMIA would appoint the journal Editor after discussion with the publisher; that AMIA would have control of the scientific content of the journal; and that journal content would include material appropriate to the organization and to the field of informatics. AMIA membership at the end of 1990 was 1,124; at the end of 1991 it was 1,911. Lindberg completed two subsequent 2-year terms on the AMIA Board (one was as Past President) after his initial 1989-91 term as founding AMIA President ended. As the above details reveal, Don's leadership, dedication, and inspirational example were key elements in the early initiation and success of AMIA.

Jan van Bemmel, although not an American, can testify to Don's diligent diplomacy, having been present at the meeting where the decision was made to incorporate SCAMC, ACMI, and AAMSI into a new organization, thereby creating AMIA. This meeting took place in 1988 on top of the San Francisco Hilton, the same place where MEDINFO 2004 would be hosted by AMIA 16 years later. Marion Ball joined the Board of AMIA and later formed the bridge from AMIA to the International Medical Informatics Association, IMIA.

3.2 IMIA and MEDINFO

Started by Parisian informatician François Grémy, MD, the *International Medical Informatics Association* (IMIA) came into existence in 1967, within the *International Federation for Information Processing* (IFIP), as Technical Committee 4 (TC4), a special interest group. In the early 1980s, Lindberg was appointed to serve as the U.S. representative to IMIA by the American Federation of Information Processing Societies (AFIPS). Don remained involved with IMIA and participated as an active proponent. While still at the University of Missouri, Don accepted an invitation to chair the organizing committee for the upcoming 1986 MEDINFO – IMIA's triennial international meeting. Van Bemmel chaired the program committee, with Shortliffe as vice-chair. Lindberg asked Piemme and SCAMC to host the meeting in Washington, DC. The meeting was highly successful nationally and internationally.

Lindberg used his experiences with AAMSI and IMIA (in part) as a model for how he organized AMIA. Subsequently, the U.S. again hosted MEDINFO in 2004 in San Francisco, this time through AMIA. Dr. Lindberg was instrumental again – as in the past. In the background, he helped to arrange for NLM's Fogarty International Center to provide support for as many people as possible from Third World countries to participate in MEDINFO. He also had done so for preceding MEDINFOs. The title of that 2004 MEDINFO, Building High-performance Healthcare Organizations, fit very well with Don's vision for high performance computing in biomedicine.

3.3 HON, Health-on-the-Net

The *Health-on-the-Net Foundation* (HON) was created in 1995 in Geneva by Jean-Raoul Scherrer, MD, PhD. HON became one of most respected not-for-profit portals to medical information on the Internet. It not only widely opened medical and health information to the general public, but also incorporated a Code of Conduct, the *HON Code.* Sites could apply to be audited, reviewed, and endorsed by HON. The presence of the HON Code logo on a health-related Web Site ensured that medical information offered on it conformed to the principles of trustworthiness and reliability embodied in the HON Code. Lindberg served as the President of the HON Council during its early years, after Scherrer.

van Bemmel and Ball also participated in the Council of Health on the Net. Most Council meetings took place annually in Geneva and surroundings, first operating under the leadership of Scherrer, and later under the guidance of Dr. Celia Boyer. HON was extraordinarily successful and won the European Award for e-Health.

3.4 Methods of Information in Medicine

Over many years, Lindberg and van Bemmel served as joint Editors-in-Chief of the oldest journal in the informatics field – *Methods of Information in Medicine*, or in shortened form, '*Methods*'. In 1988 they took over the helm from Dr. Gustav Wagner from Heidelberg, founder and first Editor-in Chief, who had originally started the journal three decades earlier in the German language before transitioning after several years to English. Lindberg and his colleagues have been supportive in stimulating the worldwide visibility of this journal and have authored many leading contributions in its pages.

4. NLM and Informatics

Under Dr. Lindberg's leadership, the NLM became the world's largest fully digital biomedical library. The Library has a statutory mandate from the U.S. Congress to apply its resources broadly to the advancement of medical and health-related sciences. It collects and organizes biomedical information, and makes it available to investigators, educators, and practitioners, while carrying out programs designed to strengthen existing medical library services and develop new information dissemination methods in the United States. Dr. Lindberg's and NLM's roles in those activities are detailed elsewhere in this book, including the outreach efforts for NLM bibliographical content embodied in the Grateful Med and PubMed interfaces. During the years 1992-95, Don was also the Director of the *National Coordinating Office for High Performance Computing and Communications* [8]. In addition, he served from 1996 to 2000 as the US Coordinator for the *G-7 Global Health Applications Project*, nominated by the Secretary of the United States Department of Health and Human Services (DHHS).

A valuable feature of NLM is its internal research and development activities. The latter are carried out in NLM's *Lister Hill National Center for Biomedical Communications* (LHC) and the *National Center for Biotechnology Information* (NCBI) [9]. The NCBI is the result of long-range planning that Don undertook in the 1980s. His contributions to many such NLM initiatives are detailed in [6]. They all have had a profound impact on the informatics discipline as well as on the informatics meetings and organizations that we have earlier discussed.

5. Some Private and Personal Observations

Don played a pivotal role in the early development of working groups within the International Medical Informatics Association (IMIA). He helped establish the very first Hospital Information Systems working group that was formed in Cape Town, South Africa in 1979. Not only did Don contribute great value to many international initiatives, spanning many countries around the world; he also had the gift of being an unusually caring husband and father. Don, on most of his national and international trips, took one of his three sons with him to broaden that boy's world view and to allow him to experience varied cultures, both in the United States and abroad – part of what he considered important for each son's education.

We can say that the tremendous professional contributions that Don has made on an intellectual and academic arena can also be equated with the humanity and humility that he demonstrated throughout his entire life. Don was truly a man for all seasons, with a scientific way of thinking and contributions that will live on for decades to come, reflecting not only how he served as a physician and a professor, but also as one of the longest tenures of leadership for an NIH institute.

Another special and less known fact about Don's accomplishments is he was a talented photographer, taking superb pictures all over the world. He published several volumes of his exquisite photographs. Many of them hang in various areas of the National Library of Medicine. The *Memoirs* section of this book provides additional details regarding the above comments.

We cannot end without saying that Don never underestimated the importance of his wife Mary, to whom he was utterly devoted. She was, indeed, the wind under his wings. Mary is a nurse who provides home care as a Hospice Volunteer.

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NLM and the IAIMS Initiative: Cross-Institutional Academic/Advanced Systems Contributing to the Evolution of Networked Information and Resources

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Abstract. The Integrated Academic/Advanced Information Systems (IAIMS) program began in 1983 and was based on a study by the Association of American Medical Colleges (AAMC). Donald A.B. Lindberg M.D. was a member of the AAMC Advisory Committee. The U.S. National Library of Medicine (NLM) grants for IAIMS were initiated in 1984 the same year Dr. Lindberg became Director of the NLM. This chapter presents an overview of IAIMS and its progression through three stages with Dr. Lindberg's leadership.

Keywords. IAIMS, Integrated Information, Integrated Resources, National Library of Medicine (NLM), Medical Libraries, Association of American Medical Colleges (AAMC)

In memory of Richard T. West, MLS, IAIMS Program Officer

1. Introduction

The Integrated Academic Information Management Systems (IAIMS) initiative was a significant strategy by the U.S. National Library of Medicine (NLM) to strengthen medical libraries and librarians and their respective roles. Later in the evolution of IAIMS the word "Academic" was changed to "Advanced" to recognize the applicability to both clinical and academic components of health science centers and the importance of advanced technologies.

To understand the role of IAIMS in information management and the role of Donald A.B. Lindberg, M.D.'s leadership it is critical to understand the background and context of the IAIMS effort. This chapter begins by sketching the environmental context of medical libraries in the 1960's and 1970's including passage of the Medical Library Assistance Act and establishment of the Lister Hill Center for Biomedical Communication within the NLM. Section three describes the emergence of the concept of integrating information in response to this rapidly changing environment and sets the stage for the NLM's launch of the IAIMS program in 1983. Section four presents the evolution of IAIMS under Dr. Lindberg's leadership from the initial concept to wide-

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spread implementation. It highlights Dr. Lindberg's use of strategic planning to catalyze implementation of concepts and strategies. Section five outlines the influence of the IAIMS program on the organizational fabric of participating academic health science centers and in nurturing national scale collaboration and consortia activities. Section six describes the impact of Dr. Lindberg's leadership on IAIMS and the impact of IAIMS on Dr. Lindberg as Director of the NLM. The chapter closes by reporting four enduring lessons from the IAIMS program.

2. Environmental Context of Medical Libraries before IAIMS

In 1963, Harold Bloomquist, MLS, Assistant Librarian at the Harvard University Medical Library conducted a study of the status and needs of 86 medical school libraries for the National Library of Medicine. His findings indicated that investment in medical libraries had not kept pace with growth of research, specialization, and multi-disciplinary science. He highlighted the profound effect of these changes and growth rates on biomedical communication and reported that scientists and other library users "encountered so many difficulties in working with the traditional library system that they have tended to neglect the use of formal published information sources and have developed a number of other devices to obtain the required information." The report recommended federal support of "the essential bibliographic apparatus needed in medical research" with NLM taking national leadership, including "a system of regional reservoir libraries", programs for training librarians and matching grants for library construction [1].

2.1. The Medical Library Assistance Act (MLAA) and the National Library of Medicine (NLM)

The U.S. Congress passed the Medical Library Assistance Act (MLAA) in 1965. This legislation enabled the NLM to initiate programs to assist the nation's medical libraries and to develop a medical library network with the establishment of regional medical libraries to link the NLM with local institutions. This act catalyzed construction or expansion of 86 health science libraries from 1966 to 1975 [2].

The Lister Hill Center for Biomedical Communication was established within the NLM in 1968 by Senate Joint Resolution to develop networks and information systems to improve health education, medical research and the delivery of health services. The question of content, what messages shall be communicated and who is responsible for determining what these messages shall be, was central to any plans for the new center. NLM contracted with the Association of American Medical Colleges (AAMC) to provide recommendations about content development and furthering relations between the NLM and the academic medical community. The Steering Committee, chaired by Eugene A. Stead Jr., MD. consulted over 100 individuals and visited ten medical schools. The 1971 report recommended that "The Lister Hill Center should have as its eventual goal the development of education methods which will render obsolete the current systems of libraries, textbooks, medical school curricula, and total dependence on memory and pattern recognition in clinical decision making and problem solving." It also recommended the Center fund approximately ten regional medical divisions of computer

science in medical centers with strong university programs to develop needed manpower [3].

3. The Association of American Medical Colleges Study: Toward the Concept of Integrating Information

In 1979, the National Library of Medicine contracted with AAMC to explore the future of librarianship, with the question of technology looming on the horizon [4]. The report of that study, co-authored in 1982 by Nina Matheson, M.L.S., and John Cooper, M.D., was titled *Academic Information in the Academic Health Sciences Center: Roles for the library in information management* [5].

They reported that academic health science centers "information support systems are fragmented mixtures of single function, manual, and computer-based files that can neither communicate nor exchange information effectively." They recommended that: academic centers implement a network that facilitates the flow of recorded knowledge throughout their institutions with the "library as a primary node"; professional associations link academic, administrative and organization information bases to hospitals and individual practitioners; and industry, foundations and federal agencies develop prototype network systems and programs that encourage the rapid integration of information technology (IT) in the learning and practice of health professions, programs that attract and retain qualified people in medical information and knowledge-base development in academic centers.

The study had an advisory committee for direction and advice. Since Dr. Lindberg had been a member of the Biomedical Library Review Committee (BLRC) in the late 1970's, he was invited to be a member of the advisory committee by the AAMC. Dr. Lindberg understood the issues outlined in the AAMC's report. The report provided a foundation that led to the National Library of Medicine under his leadership to continue and enhance the IAIMS strategy.

4. The National Library of Medicine: IAIMS Initiative

Responding to the report from the AAMC, the National Library of Medicine embarked on a long range Integrated Academic Information Management System (IAIMS) prototype development program to develop models for designing and effectively managing information at large-scale for health care institutions.

The goal was to catalyze development of programs and products so that the needed and appropriate information would be available where and when required to support research, education and/or patient care. IAIMS placed health science institutions in the forefront of information systems integration and communications networking. In 1992, Dr. Lindberg wrote "IAIMS has been a significant initiative and notable success in developing organizational mechanisms to manage the knowledge of medicine [6]."

This chapter describes the evolution of IAIMS from its initial concept to wide-spread implementation in three stages. Throughout the stages strategic planning "drove" the implementation concepts and strategies. The three stages are: Exploring, Clarifying and Expanding, and Mainstreaming.

4.1. Exploring; IAIMS First Generation

In 1983, the NLM issued a request for proposals to conduct institution-wide strategic planning for information resources management. Four contracts were issued to Columbia University, Georgetown University, University of Maryland at Baltimore and the University of Utah. Later that year, the Medical Library Association published a special issue to familiarize the health science library community with the AAMC report [7]. The multiple articles explored an overview of IAIMS, as well as implications for planning, access, delivery and the role of libraries and librarians [8-10].

In 1984, when Dr. Lindberg became Director of the National Library of Medicine, he established a long-range planning group for the NLM. That group was organized into 5 panels: (1) Building and Organizing the Library's Collection: Robert M. Hayes, PhD (2) Locating and Gaining Access to Medical and Scientific Literature: Nancy M. Lorenzi, PhD (3) Obtaining Factual Information from Data Bases: Ruth Davis, PhD. (4) Medical Informatics: Edward H. Shortliffe, MD PhD, (5) Assisting Health Professions Education Through Information Technology: G. Octo Barnett, MD

Panels 2 and 4 included goals that impacted NLM's IAIMS strategy. Panel Two supported NLM's efforts "to develop technologies related to knowledge-based systems and recommended improvement in disseminating biomedical information." Panel Two stressed that "IAIMS projects created effective models and that IAIMS provides an effective process and framework for implementation [11]."

The Panel Four report stressed that in the future computers will be routine in health care. The report indicated that the lAIMS program had led to an increased awareness of the clinical role of computers and that individual academic institutions had begun to grapple with issues of instructional and research computing, administrative data processing, information dissemination, and communication within the medical center, the need for expertise in the area of medical informatics has become increasingly evident to administrators [12].

After issuing the initial contracts, NLM switched to IAIMS grant mechanisms, encompassing three phases: planning, model development to test to evaluate the results of the planning process, and implementation. The IAIMS grantee institutions completed demonstration projects to improve information access and utilization. These early efforts led to new capabilities for medical informatics to support the health care system.

In October 1984, NLM held a symposium to introduce the efforts of the four contracts recipients [13]. Dr. Lindberg introduced the symposium with his hope for the future: "a lot of what we will hear today has to do more with arrangements between people and the managing of institutions than it has to do with the technology of the systems…technology is better now…attitudes are different from those of twenty-years ago. The institutions too are more ready to utilize what the computer has to offer…this is interesting and exciting, but I offer one cautionary note. I hope that in …these energetic experiments we will not find ourselves slipping into the error of adapting people to computers and adapting institutions to systems. That is exactly the reverse of what we ought to do. Our medical institutions will have to change…they should not change because of the computer, but because of what information systems and humans can do synergistically and because of their changing needs as complex institutions. Perhaps the IAIMS planning opportunity will help us to achieve this desirable outcome."

By 1991, twelve IAIMS grants had been awarded to: Baylor College of Medicine, University of Cincinnati, Duke University, the American College of Obstetrics and Gynecology, Johns Hopkins University, University of Pittsburgh, Dartmouth University,

the University of Michigan, Rhode Island Hospital, Oregon Health Sciences University, the University of Washington, and Tufts University.

4.2. Clarifying and Expanding: IAIMS Second Generation

In 1992, Dr. Lindberg predicted that "the future for the IAIMS concept will be one of growth" [6]. He highlighted three drivers: increased awareness among administrators, health care workers and researchers of the power of computers to provide facile access to information essential to decision making; national interest in the computerized patient record requiring mini-IAIMS for hospital and clinic; and the federal government's High Performance Computing and Communications (HPCC) initiative opening the doors to nation-wide IAIMS collaborations and advanced molecular biology computing, imaging, drug design and educational technologies. Additional details on HPCC appear in separate chapter of this book.

A few months later, NLM introduced a significant revision to the IAIMS program to incorporate lessons from the first decade, and to accommodate the changing environment. The announcement changed the name of the program by replacing *academic* with *advanced*. This change recognized the broad applicability of the IAIMS concept and the need to incorporate emerging technologies. The revision reduced the potential duration of funding from ten years to seven. It retained the planning phase from the original program, and fused the modeling and implementation phases into a combined operational phase. It provided the flexibility to include operational elements during planning. The announcement required involvement of all components of the institution, including a clear relationship to clinical aspects of the health sciences; a plan for developing the institution's information management resources, and requisite networks; a functional information policy; designation of leadership with appropriate background and status; timetables for reaching key features of the plan; the ability to provide efficiently bibliographic and related literature; significant participation by the health sciences library; substantial incorporation of elements of HPCC. It included an option to add an IAIMS apprenticeship during the operational phase to build IAIMS workforce capacity.

NLM received over 200 inquiries in the first month after the program announcement, the majority from individual hospitals or associations of hospitals. Richard T. West, MLS, IAIMS Program Officer at the NLM, worked tirelessly to encourage institutions to prepare planning grants and to coach them through the process. Preparation of an application involved organization-wide conversations about leadership, policy and planning that often changed the trajectory of an organization even when the application was not funded. Sites funded for both planning and operational second generation IAIMS projects included City of Hope National Medical Center, Vanderbilt University, University of Medicine and Dentistry of New Jersey, University of Missouri at Columbia, University of Pittsburgh, University of Washington and Yale University. These institutions represented a wide range of organization structure and balance of clinical and academic activities. Each grappled with how to develop an IAIMS that could scale up to enterprise-wide use and evolve in the face of rapidly changing technology and business environments. The key lesson from these projects was the importance of core of enterprise-wide planning and policy formulation functions to guide decision making at all levels of the organization [14]. Support for envisioning the future, organizational development, strategic planning, technology forecasting, development of

information policy, specification of reference architectures, and development of strategic partnerships has always been critical to any successful IAIMS effort.

4.3. Toward the Third Generation IAIMS: The AAMC's IAIMS The Next Generation Report

In 1998, NLM contracted with AAMC to examine the IAIMS concept as articulated by Matheson and Cooper, its implementation in the IAIMS grant program of the NLM, and the effect of the IAIMS grant program on information practices in academic health science centers. The 20-month study process was led by Valerie Florance Ph.D. It included citation analysis, focus groups, site visits and an advisory "think tank group" chaired by Daniel Masys M.D. [15].

The study concluded that then-current academic health sciences centers were richly endowed with networks and electronic resources that were not dreamed of in the 1980s. While the basic mission and goals of academic centers had not changed, the resources that support those missions had become fundamentally different. With access to data, information, and knowledge no longer time and place dependent, new opportunities had emerged to improve the way health care, research and education are carried out. To benefit from these opportunities, attention needed to turn to a new set of challenges.

Among these, two were of special importance. First was the challenge of seamlessly integrating an institution's own information resources with relevant information obtained from sources outside the organization that are not controlled by it. Second, while the challenge of the 1980s was building infrastructure and organizational mechanisms for managing knowledge, the challenge of the 21st century had become acquisition and shaping of that knowledge such that it binds to effective action. The site visits found participants in the NLM program had valued IAIMS planning; endorsed creation of a flexible pool of funds to direct toward unanticipated opportunities for collaboration; had created branded, sustained activities inside the organization; and had supported development of an academic informatics unit. The report recommended the NLM IAIMS program should be updated to serve as a stimulus for the development and adoption of tools and techniques for information management in the 21st century. Using technology to enable the application of knowledge – to improve health, to enable good decisions, to enhance learning, to aid discovery and innovation - should become the central focus of IAIMS in the coming decade.

In 2002, NLM responded by revising the scope and structure of the program. IAIMS was redefined as organization-wide or trans-organizational mechanisms that use computer networks to link and relate the published biomedical knowledge base with individual and institutional databases and information files, within and external to an institution. The sequential planning and operational phases were replaced with a portfolio of grant mechanisms to support IAIMS planning, pilot studies, testing or evaluation, operations, or fellowships. Institutions could pick the appropriate entry point for their situation and use multiple IAIMS mechanisms and RO1 mechanisms for related work. The program announcement highlighted context-appropriate information delivery, standards-based information and digital libraries as current areas for focus. Over the next seven years, the NLM funded 15 planning grants, 1 pilot study, 3 test and evaluation projects, and 4 operations grants.

4.4. Mainstreaming: NLM's Long Range Plan Charting a course for the 21st century (2006-2016)

In 2004, Dr. Lindberg invited William Stead M.D. and Hon. Newt Gingrich Ph.D. to co-chair the NLM Board of Regents Subcommittee on Planning. Their charge was to develop a new Long-Range Plan for 2006-2016. He narrowed the planning goal to ten years because "few will see the rapidity with which our local science world and our larger geo-political world is changing [16]." Dr. Lindberg accepted the subcommittee's suggestion, based on lessons from IAIMS, that the planning should begin with a longer, quite unconstrained strategic vision. A two-day visioning session in April 2005 explored what the world of health and biomedicine might look like in 2025. The vision for NLM that emerged reflected "the fundamental observation that publication and reading are necessary but insufficient mechanisms to turn knowledge into effective action in the 21st century. A healthcare enterprise that depends primarily on the cognitive capacity and reliability of autonomous individual practitioners and their interpretations of what they read will continue to be error prone and have unacceptably high rates of suboptimal disease prevention, diagnosis, and treatment. In the future the informed and activated consumer will play an increasingly important role in error prevention. A systems approach to health care and public health will depend increasingly on executable knowledge in the form of computerized logic that embodies the collective best understanding and practices for health-related practices. Stated differently, in addition to patients, families, and the public, the Library's fastest growing group of users may be intelligent devices."

This vision jump-started the work of four planning panels focused on: resources and infrastructure; health information for underserved and diverse populations; support for clinical and public health systems; and support for genomic science. These panels developed detailed reports with goals and recommendations for their focus area. Next, a special planning group reviewed these four reports to identify cross-cutting issues for informatics research that emerged from the 4 panels. Then NLM staff and the Board of Regents Planning Subcommittee stepped back and identified four overarching goals: seamless, uninterrupted access to expanding collections of biomedical data, medical knowledge, and health information; trusted information services that promote health literacy, improve health outcomes and reduce health disparities worldwide; integrated biomedical, clinical, and public health information systems that promote scientific discovery and speed the translation of research into practice. This iterative planning process, alternatively zooming out-in-out is an example of Dr. Lindberg applying IAIMS-related techniques directly across the NLM.

5. IAIMS Governance and Connections

The first generation IAIMS program focused on technology to help academic medical centers understand the potential of computers and networks to increase information access and use. As understanding of the power of connected computers increased, the IAIMS program shifted to focus on changes in organizational structure and processes, infrastructure and skill sets required to allow management of information as a collective resource and flow of information across boundaries. The second generation focused on organization change within large academic health centers. The third generation expanded

scope of IAIMS to inter-institutional connections and connections to national or international resources.

From the beginning of the program, IAIMS changed the organizational fabric of participating academic health science centers. Senior leaders came together from across the organization and engaged in conversations with the library director and information technology leaders to develop a credible IAIMS grant proposal. Often these people were at the same table for the first time. The first step involved structuring an interdisciplinary team to lead the IAIMS planning project. IAIMS planning brought people together from different mission areas and levels of the organization to develop a shared vision for the future and a plan to move in that direction. They discussed potential changes in policy and resource allocation to remove barriers to the plan, and their willingness or resistance to the change. IAIMS project structures were often replaced by permanent structural changes during the transition to the operations phase to scale-up organization-wide information management capabilities. Over time, IAIMS organization development principles were hard-wired into the way the organization managed large scale strategic change.

In 1989, six of the institutions funded by the NLM to develop 1st generation IAIMS models self-organized a communal workshop that fostered communication among their teams and identified opportunities to transfer expertise or technology between sites [17.] They defined standards to increase transportability and developed cooperative multicenter projects to evaluate techniques or technologies needed by multiple sites. Four of the institutions were competing for funding in the next year and each institution had to pay their expenses since the workshop was not externally funded. The six sites' Principal Investigators believed they could use what they had learned working across boundaries within their organizations to collaborate across institutions to make the collective effort more than the sum of its parts. The IAIMS Consortium emerged from this workshop. By 1996, the Consortium included 25 institutions interested in IAIMS, broadly defined, not just NLM-funded sites.

The structure of the third generation of the NLM IAIMS grant program assumed that institutions would have a foundation of IAIMS-like organizational development functions and infrastructure in place. The portfolio of IAIMS funding mechanisms supported targeted planning, prototyping, evaluation, and training projects to plug into that foundation. Similarly, the R01 research grant mechanism could be used for IAIMS-related investigational projects that leveraged an existing IAIMS foundation.

6. Donald A.B. Lindberg's Impact on IAIMS and the Impact of IAIMS on Donald A.B. Lindberg

The IAIMS program was continuous throughout Dr. Lindberg's tenure as the Director of the National Library of Medicine. In reviewing materials about IAIMS, it becomes clear that while Dr. Lindberg's leadership had a major impact on IAIMS, the concepts of IAIMS had a major impact on him and his initiatives as Director of NLM.

6.1. Dr. Lindberg's Leadership Impact on IAIMS

Dr. Lindberg convened three long-range NLM planning initiatives (1984, 1992, 2004 plus the 1998 IAIMS—The Next Generation AAMC study). While IAIMS-related

components were included in each planning initiative, their significance grew in prominence in each successive long-range planning process.

During the early Exploring stage, the IAIMS academic sites completed many demonstrations of integrating information and resources. By the Clarifying and Expanding stage, NLM changed its processes for more rapid planning and implementation. At this stage, more organizations were interested in the possibilities of IAIMS. The culmination of the acceptance and spread of the underlying IAIMS-related concepts of was central to the Third Generation, mainstreaming IAIMS-derived ideas through the NLM's long range plan: Charting a course for the 21st century (2006-2016).

6.2. IAIMS Impact on Dr. Lindberg as Director of the National Library of Medicine

By 1984, the Medical Library Assistance Act was 20 years old, and a robust network of Regional Medical Libraries was in place. During the course of his NLM leadership, Dr. Lindberg progressively elevated IAIMS from an NLM program to support work by other organizations, to a conceptual framework that he could apply to the NLM system when appropriate. Dr. Lindberg turned aspects of the entire NLM system into a global IAIMS through iterative long-range planning and pragmatic accomplishments. Sample projects and dates support this idea (see additional chapters in this book for details):

- 1986: Unified Medical Language Systems (initiated)
- 1986: Visible Human Project (initiated)
- 1988: National Center for Biotechnology Information (NCBI) (initiated)
- 1996: Stable web browsers led to PubMed and the first internet access to Medline
- 1997: PubMed Central opened free to the world (from MEDLARS-to Medline-to PubMed Central)
- 2000: Clinical Trials Registry
- 2001: RxNorm

7. Summary

The IAIMS initiatives significantly changed institutional strategies from a time when biomedical information was managed in silos to a time when biomedical information was extensively integrated and inter-connected with other types of information critical to support effective action. Donald A. B. Lindberg saw the possibilities of IAIMS from the initial Cooper-Matheson report about issues to be solved. He worked to address those issues throughout his tenure as Director of the National Library of Medicine.

7.1. Paradigm Shift

Early reports from the 1963 Bloomquist report to the initial AAMC IAIMS study indicated that information users were frustrated by their inability to locate the needed information to do their work. Stead, in a 1997 summary article, indicated that users still found information access problematic, and that "we need to help them, but if we focus on that alone we are putting all of our energy into fixing past decisions about how to use old technology. We have to help those people step past today's problems, to think with us about how they want to work in totally new ways that can be enabled by the kind of

information access that we can now support. Once that vision is clear, we can see how to move from where we are to where we want to be in a way that solves today's problems incrementally" [14]. IAIMS shifted the paradigm. It was a key initiative that demonstrated the importance of interconnecting people, processes, and technology to provide needed information and actions.

7.2. Building Infrastructure

Institutional infrastructure must include technology, people, information, and organizational components. While some institutions may have seen the price tag of integration and coordination as high, the overall costs were potentially similar to what was previously spent in an uncoordinated manner that did not connect or synergize the whole. Without an interconnected infrastructure, users could not have access to the needed information. An IAIMS plan provided institutions with a road map to align individual investments to build a foundation of reusable infrastructure.

7.3. Working Across Boundaries and Cultures

Healthcare organizations consist of multiple sub-component organizations. For success with integrated information, organizational sub-components had to work together for success. This meant more effective interconnection of people. IAIMS provided the "push" to internal connections by expecting organizations to work internally as well as externally.

7.4. Effective Change Management Strategy

IAIMS essentially provided a strategic change management process for an organization to develop the needed integrated information, services, products, and people. By the cooperation for planning, developing demonstrations and integrating external information, the people in an organization came to appreciate the benefit of IAIMS and the need to work differently and together. Dr. Lindberg saw the possibilities of IAIMS and became its chief proponent externally and internally for the National Library of Medicine.

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Don Lindberg's Influence on Future Generations: The U.S. National Library of Medicine's Biomedical Informatics Research Training Programs

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Abstract. Through his visionary leadership as Director of the U.S. National Library of Medicine (NLM), Donald A. B. Lindberg M.D. influenced future generations of informatics professionals and the field of biomedical informatics itself. This chapter describes Dr. Lindberg's role in sponsoring and shaping the NLM's Institutional T15 training programs.

Keywords. Donald A.B. Lindberg, U.S. National Library of Medicine, Biomedical Informatics Training.

In memory of Milton Corn M.D. 1929-2021. Director of the Extramural Programs Division, U.S. National Library of Medicine 1990-2009; Deputy Director for Research and Education 2009-2021.

1. Introduction

Donald A.B. Lindberg M.D. influenced successive generations of trainees in the field of biomedical informatics during three decades as Director of the U.S. National Library of Medicine (NLM). This chapter describes how Dr. Lindberg's visionary leadership both enabled and shaped training in biomedical informatics from 1984-2015. The chapter will not describe in detail the NLM Informatics Short Course or separate training opportunities offered by NLM to librarians or by the National Center for Biotechnology Information (NCBI) [1].

Prior to Dr. Lindberg's arrival at NLM, the Medical Library Assistance Act of 1965 had authorized NLM to provide grants for post-baccalaureate academic training in medical library sciences, in related fields pertaining to sciences related to health, and in the field of the communication of information [2]. By 1969, an annual budget of $1.3 million was allocated among 11 universities for development of graduate and

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postgraduate training programs for health science information and communication specialists [2]. Four of those programs supported 11 Ph.D. candidates for careers in health information research.

In 1972, NLM and the Bureau of Health Manpower Education cooperated to support the training of physicians and other health scientists in the use of computer technology for medical education and the provision of health care [2]. Those early training programs differed significantly from current NLM T15 grant-based training programs, as the 1976 NLM Annual Report clearly explained:

> "The National Library of Medicine supports the training of health scientists in computer technology. The ultimate goal … is to promote the complete and effective integration of computer technology into all phases of clinical medicine, teaching, practice, and research. Except for a few unusual people, most do not find it possible to master two disciplines well enough to provide innovative leadership in either … Therefore, the most practical projects to be supported are those for teachers or potential faculty members in the health sciences. By incorporating new ideas into their teaching, they will multiply the process of dissemination. Depending on the academic background and experience of the faculty member being trained, one or two years of guided study should suffice to provide him with insight into the potential of computer techniques. The training should equip him to recognize where computers can be of assistance in the solution of medical problems, to communicate his needs effectively to computer consultants, and to understand and use the computer assistance provided [3]."

By 1980, grants for 76 individual trainee positions (36 pre-doctoral, 39 post-doctoral) were awarded via this program to 10 institutions [2]. In 1982-83, the NLM Board of Regents decided to sponsor institutional grants that focused on research training rather than the previous mechanism of grants that supported training of specific individuals [4]. In 1984, five awards were made in the new Health Computer Sciences Research Training program (detailed below) [5].

When Dr. Lindberg was sworn in as NLM Director in October 1984, he had already gained a significant understanding of NLM's programs through earlier service on the NLM Board of Scientific Counselors (1983-84) and the NLM Biomedical Library Review Committee (1976-80). At Dr. Lindberg's first NLM Board of Regents (BOR) meeting in October 1984, his presentation stimulated a discussion among BOR members regarding the need for long-range planning [6]. The BOR then formally requested creation of such a plan. Central to Don's emphasis on training was the NLM Long-Range Plan of 1986. The presentation of the plan to the BOR in 1986 stated that: "NLM should assume leadership in the medical Informatics area, become a 'National Institute for Medical Informatics;' … training in medical Informatics should be encouraged in schools of the health professions" [7].

2. Don Lindberg's Ongoing Personal Influence on NLM Institutional Training Programs

Dr. Lindberg saw the NLM Institutional Training Program as a commitment and opportunity to build the nascent community of informatics professionals. NLM sponsored an annual training meeting that brought faculty and trainees from all the NLM-funded training sites together. The NLM annual training meetings were designed to

encourage faculty and trainees to interact socially, to exchange ideas, and to build a sense of community among them. Dr. Lindberg also viewed the annual training meetings as a forum to introduce faculty and trainees to the opportunities provided by NLM for support of their future research.

The formal components of the earliest NLM annual training meetings included a gathering of all attendees in an auditorium at NLM with prominent plenary session speakers, including Don himself as the leadoff presenter. Subsequent days of the training meeting were reserved for lecture and poster presentations by trainees. Don also hosted a break-out session for the Training Program Directors at each meeting to review operational issues at NLM and at each site, to present future funding outlooks, and to exchange suggestions for changes/improvements.

In his keynote presentations, Don would summarize the state of the field, highlight current initiatives at NLM, and point out what he saw as future research prospects. For example, during the 1990 Annual NLM Training Meeting plenary session, Don exhorted everyone present (faculty and especially trainees) to consider expanding their individual careers and their training programs to encompass bioinformatics. That was the first time many individuals in the audience heard of NLM's recent commitment to the domain - embodied in the new National Center for Biotechnology Information [8].

An important social component of the meetings was the annual picnic, typically hosted by Don and his wife, Mary. In the earliest years, they hosted the afternoon and evening get together with a cookout at their Potomac area home. Many of the trainees enjoyed swimming in the Lindberg's back-yard pool. When the program expanded over the years to outgrow the capacity of the Lindberg's house, the venue for the social event changed to the picnic grounds behind the (then) Bethesda Naval Hospital at the Uniformed Services University of the Health Sciences Medical Center. Volleyball games and horseshoe tossing contests included program directors, faculty, and fellows. By combining both formal meetings and social events, these became very meaningful events to the trainees. In addition, trainees were thrilled to meet and interact informally with Don and with training directors and faculty from other universities.

After the initial five years of annual training meetings had been hosted at NLM, a decision was made to alternate the meetings between NLM and one of the training program sites that volunteered to serve as host for a given year. The host sites spanned the U.S., giving trainees the opportunity to see firsthand how informatics was manifested in different environments. Each host site also took pride in sponsoring a picnic or dinner at a noteworthy local attraction. For example, when the Harvard-MIT program hosted the meeting, the social event included a clambake in the courtyard outside the Harvard medical library. When Yale hosted the meeting, dinner attendees were treated to a Yale Glee Club performance.

The initial training programs focused on clinical informatics. It was Don's foresight that contributed greatly to broadening the field eventually into biomedical informatics, by calling attention to the growing work in molecular science and genomics and activity centered around bioinformatics at NIH. During Don's tenure at NLM the scope of the programs expanded to include high-performance computing and computational complexity, vocabulary and terminology, public health, and toward the end of his time at NLM, biomedical data science.

3. Growth, Diversification, and Evolution of the NLM Institutional Training Programs

One of the features of the NLM-sponsored training programs from 1984 onward was the specific focus on research training [2]. Trainees were expected to undertake academic study at the doctoral or postdoctoral level, and to prepare for careers that would advance the field. This was very important for a growing field in which prior leaders had been largely self-taught through ad hoc coursework and on-the-job experience. At the time of the initial training programs, it was already recognized that biomedical informatics was a cross-disciplinary field that drew on several other disciplines, including computing, psychology, statistics, biomedical science, and clinical medicine, among others. Curricula were just beginning to be developed, as well as formal degree programs. Some historical Training Program highlights (derived from the NLM Annual Reports and Minutes of the NLM Board of Regents Meetings) follow below.

Prior to Don Lindberg's arrival at NLM, the first institutional research-focused grants made through the new Health Computer Sciences Research Training program supported five sites, as noted in the introduction. The 1984 awards included: University of California, San Francisco School of Medicine (PI: Marsden S. Blois M.D., Ph.D.); University of Minnesota School of Medicine (PI: Lael Gatewood Ph.D.); Harvard University (PI: Robert A. Greenes M.D., Ph.D.); Tufts-New England Medical Center (PI: Stephen G. Pauker M.D.) and Stanford University School of Medicine (PI: Edward H. Shortliffe M.D., Ph.D.) [5]. The five institutions enrolled 21 individuals initially, subsequently ramping up to more than 50 trainees per year. The awards primarily focused on postdoctoral research training, including individuals with prior M.D.s, some with Ph.D.s, as well as individuals in M.D.-Ph.D. programs. In later years, programs could request funds for three-month short-term trainees, such as medical students, to give them exposure biomedical informatics as a possible career path.

NLM's training programs were re-competed in 1987, to have a broader biomedical informatics research focus, to include biotechnology informatics as well as clinical informatics [9]. The program was expanded to eight institutions, with support for more than 70 trainees, still predominantly postdoctoral in emphasis, but now providing support for doctoral candidates as well. A re-competition in 1992 resulted in 10 training sites, some of which were now multi-institutional. Trainee count expanded to more than 100 trainees per year. The National Cancer Institute (NCI) contributed support for four trainees per year [10]. The 1997 round of funding resulted in awards to 10 training sites again, with several again multi-institutional [11]. Trainee count was now over 150 per year. Some of the NLM training slots focused on radiation oncology funded by NCI and for dental informatics funded by the National Institute of Dental Research (NIDR). The final year of NCI support was 1999.

In 2002, 18 programs were funded for next five-year interval. More programs emphasized bioinformatics, and with partial support from the National Institute of Biomedical Imaging and Bioengineering (NIBIB), one program emphasized imaging informatics. More than 270 trainees were being supported annually by the end of this award period. In 2005, the Robert Wood Johnson Foundation provided support to increase training in public health informatics. resulting in supplemental support to four

existing training sites to develop formal training tracks in public health informatics and for support of trainees in these tracks. In 2007, the program continued to support more than 250 trainees per year.

Collectively, the programs emphasized training in health care informatics (14 programs), bioinformatics and computational biology (14 programs), clinical research translational informatics (13 programs), and public health informatics (10 programs). Co-funding was received from the National Institute of Dental and Craniofacial Research, which supported training in dental informatics, and from the Robert Wood Johnson Foundation (RWJ) for training in public health informatics.

NLM's funding of its grant programs was downsized in 2011 [12]. This limited the number of training programs funded in the re-competition of 2012 to a maximum of 15 programs with 15 trainees or less at each site. This also included a shift to include more emphasis on bioinformatics and translational bioinformatics. The latter domains were expected to highlight connections to human health. In addition to the one new and 14 continuing sites selected, six existing programs that were not awarded new five-year grants received additional funding for one year for doctoral students early in their studies. Collectively, the continuing programs emphasized training in: health care informatics (12 programs); bioinformatics and computational biology (12 programs); clinical research translational informatics (12 programs); and public health informatics (10 programs). The National Institute of Dental and Craniofacial Research expanded support for trainees in dental informatics from two to nine trainees.

The competition that led to the 2017 training awards was influenced by NLM's participation in several NIH Big Data to Knowledge (BD2K) informatics and data science training initiatives [13]. The National Institute of Environmental Health Sciences (NIEHS) provided funding for environmental informatics trainees. The 14 university-based training programs supported 117 pre-doctoral trainees and 93 postdoctoral trainees.

As of 2018, the actively supported NLM training sites and their years of continuous support included: Yale University (32); Stanford University (35); University of Utah (22); University of Wisconsin-Madison (17); Indiana University Purdue University at Indianapolis (2); University of Buffalo (2); Vanderbilt University (17); Oregon Health & Science University (32); Columbia University (27); University of Colorado (12); Rice University (27); Harvard Medical School (27); University of North Carolina (2); University of California, San Diego (7); and University of Washington (17). In the interim from 1984 to 2018, the following sites (not listed above as initial or current sites) hosted NLM-sponsored biomedical informatics training programs for varying durations: Washington University, St. Louis; Duke University; Indiana University/Regenstrief Institute; University of California, Irvine; University of California, Los Angeles; Johns Hopkins University; University of Missouri, Columbia; University of South Carolina; MIT; and Baylor University [13].

The Training Grants were funded through the Medical Library Assistance Act portion of NLM's budget. NLM's training programs were unique at NIH in providing up to five years of funding for a predoctoral trainee, and supplemental funds for travel, training-related expenses, and health insurance. In an early period, NLM even supplemented the stipends for trainees with computer science training to lure them into

informatics. Of note, NIH rules and previous legislation had excluded NLM from using the Kirschstein T32 training grant mechanism. In years when the NLM experienced funding constraints,

Dr. Lindberg did his utmost to preserve funding to the training programs. An observation about the evolution of the programs is that, although its size and scope was dependent on NLM's funding, the allocation of funds and preservation of those funds among competing priorities owe much to Don Lindberg's commitment to the goals of training the next generation. Don also approved the various partnership agreements that resulted in co-funding of training positions by other agencies over the years. The continual reshaping and expansion of focus, plus the ongoing commitment to research training are testimony to Don's leadership and vision, and his extramural grants program staff. They recognized important new areas that expanded the scope of biomedical informatics, often before many of their colleagues were fully aware of them.

4. Outcomes of the NLM Training Programs

Over the years, as more biomedical informatics degree programs were offered at various universities in the U.S., NLM added a requirement that training-grant sponsored research fellows without a prior doctorate must obtain a doctoral degree, and that postdoctoral fellows must obtain a Master's degree. This served to emphasize NLM's ongoing commitment to advancing the academic, not just the applied, nature of the field. It is probably fair to say that most of the faculty of academically based biomedical informatics programs have come out of such training programs. When looking at the legacy of the training programs in terms of positions of leadership in healthcare organizations, informatics-focused public agencies, and business entities, the graduates of such programs also are well-represented. For example, of the institutional biomedical informatics training programs who received new five-year funding in 2017, one-third of the Principal Investigators/Training Directors were themselves graduates of NLM-sponsored training programs.

NLM sponsored a study of previous trainees' careers during the decade from 1996-2005 [2]. Forty percent had careers in academia; 18 percent had careers in business/industry; 17 percent were employed by healthcare organizations; 10 percent chose to undertake further training; and one percent were government employees. Between 1996 and 2005, 507 NLM trainees completed their training (37 percent were female); 67 percent of them had worked on research with funded researchers, and 38 percent of them published at least once with their mentor before they left the program. On average, each program received 54 applications and made offers to 24 percent of applicants; there was a 90 percent retention rate; 81 percent of core faculty had active research grants, and 38 percent co-authored papers with trainees.

Between 1996 and 2006, 51 percent of NLM trainees had been lead or co-author on one or more articles, conference papers, abstracts, or books, and they had produced 1,452 peer-reviewed publications.

NLM identified the following as valuable components of its training programs (and associated training meetings): community building (training the next generation of

informaticians); informal exchange of ideas at annual meetings; fostering collegiality among trainees at annual meetings; trainees visiting NLM as a future sponsor for their research; introduction of trainees to NLM personnel; enhancement of multi-axial diversity in the field; and scientific and educational exchange of ideas (trainee presentations at annual meetings, training directors meeting, enhancement of understanding of diverse disciplines). The benefits to institutions from NLM's training programs included: formation and growth of academic units; enhanced breadth of coverage within faculty units; and talented graduate students advancing faculty's research.

In May 2012, Extramural Programs (EP) Director Dr. Valerie Florance reported to the NLM Board of Regents that NLM's training program consumed roughly 25-30 percent of the total NLM EP budget, in comparison to the average amount that NIH overall spends on research training, which was then less than five percent [14].

5. Conclusion

The NLM Institutional Research Training Programs have been key to the expansion of biomedical informatics both academically and in organizations that rely on individuals well trained in the broad aspects of the field and its scientific underpinnings. As the discipline matured over the past four decades, NLM's training programs mirrored ongoing developments by expanding their scopes to include emerging foci such as bioinformatics, public health informatics, imaging informatics, research computing, data sciences, and other advances. During this period, NLM-supported informatics training programs also increased the academic credentials required for trainees to complete. In more recent years, this included masters and doctoral degrees to prepare trainees for research careers.

The significant allocation of funding to training and the expansion of scope over the years owe much to Don Lindberg's vision and leadership. He continued to challenge the programs with new opportunities and NLM provided the funds to respond to those opportunities. Dr. Lindberg imbued the program with a strong sense of community, which has persisted and grown through the present time.

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The Biomedical Informatics Short Course at Woods Hole/Georgia: Training to Support Institutional Change

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Abstract. The U.S. National Library of Medicine's Biomedical Informatics Short Course ran from 1992 to 2017, most of that time at the Marine Biological Laboratory in Woods Hole, Massachusetts. Its intention was to provide physicians, medical librarians and others engaged in health care with a basic understanding of the major topics in informatics so that they could return to their home institutions as "change agents". Over the years, the course provided week-long, intense, morning-to-night experiences for some 1,350 students, consisting of lectures and hands-on project development, taught by many luminaries in the field, not the least of which was Donald A.B. Lindberg M.D., who spoke on topics ranging from bioinformatics to national policy.

Keywords. U.S. National Library of Medicine, Donald A.B. Lindberg M.D, Biomedical Informatics Training, Marine Biological Laboratory

In memory of Catherine N. Norton M.S.I.S., 1941-2014.
Director, Marine Biological Laboratories/Woods Hole Oceanographic Institute Library

1. Introduction

Donald A.B. Lindberg M.D. firmly believed that the way to promote the adoption of informatics tools, resources and methods in the healthcare community was through outreach programs. Those programs exposed "change agents" from participating institutions to available informatics resources and applications and demonstrated what they could do. In 1990, Don learned of an informatics workshop that, despite being (in his opinion) of low quality, provided an inspiration for a new outreach mechanism.

This chapter describes the results of that inspiration – a short course on medical informatics, sponsored by the National Library Medicine. I will trace history of the development of the course, take a look at how the instructional topics changed over time, and try to give the reader a sense of why the course was such an exceptional experience for students and faculty who participated in it. While I cannot provide an in-depth analysis of the course's impact on the field of biomedical informatics, I reference some published work on the subject.

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In 1991, Don made a trip to the Marine Biological Laboratory (MBL), in Woods Hole, Massachusetts to learn more about MBL's research programs, Kent Smith M.A. (NLM Deputy Director) and Bradie Methany (a friend of Harlyn Halvorson Ph.D., MBL's director at the time) accompanied Don on the trip. While there, they met with Jane Fessenden, then acting director of the MBL Library (which also serves the Woods Hole Oceanographic Institute). Fessenden subsequently sent librarian and director of information services Catherine ("Cathy") Norton M.S.I.S. and biologist David Remsen Ph.D. to visit the National Library of Medicine. During that visit, Cathy got wind of Don's interest in hosting an informatics course. She suggested that Don should consider sponsoring a course at MBL [1].

The combination of the MBL's long history of biomedical education, hands-on laboratory and field work, and seaside setting struck a chord with Don. He had further conversations with Cathy, who wrote a proposal as principal investigator that led to the statement of work quoted below. The MBL hired David Stonehill Ph.D. as director the MBL/WHOI Library specifically to run the course [2]. The contract that followed was the first step in one of the NLM's longest-running and most popular outreach programs – one that ran for 23 years beyond the initially envisioned three.

> *"This 3-year project in Medical Information Outreach is designed to support the NLM's outreach efforts to the health professional community. The project consists of two phases. Phase I shall consist of three annual one-week sessions at the Contractor's site to train selected health professionals in the use of computer-assisted learning tools, accessing computerized databases, using communication networks, building and using knowledge bases for expert systems, and working with software for analyzing biologic sequence data. The potential audience for this program includes medical educators, members of the medical research communicate, graduate and postdoctoral students, health professionals from various disciplines, personnel in health agencies and associations, and staff of Regional Medical Libraries."*
>
>   *Professional Services in Support of NLM's Outreach Efforts to Encourage the Use of Computers and Information Science in Medicine – Statement of Work; December 17, 1991*

2. Year One: 1992

2.1. History of the Woods Hole Marine Biological Laboratory

The MBL was established in 1885 as a research station for the US Bureau of Fisheries in Woods Hole, Massachusetts, a small fishing village at the time, located on the southwestern-most point of Cape Cod. Situated between the Gulf Stream, which brings southern marine fauna, and Cape Cod Bay, with its resident northern fauna, the MBL was ideally placed to harvest specimens for marine biologists across the country. The disadvantages of long-distance transportation of living specimens soon led biologists to come to the site of the specimens, especially in the summer when relieved of their teaching duties. Medical researchers became interested as well, when they learned of the practical advantages of studying marine organisms, such as squid (with their giant axons),

sea urchins (with their large ova) and horseshoe crabs (with their accessible optic neurons) as models for human biology. The scholarly community grew, as research faculty brought their trainees, and the MBL began offering courses, some of which have run for over 50 years. To understand the appeal the educational experience at the MBL, read Gerald Weissmann's collection of essays in *The Woods Hole Cantata* [3].

2.2. Marine Biological Laboratory Facilities

The MBL comprises a collection of buildings around Woods Hole's Eel Pond, a tidal pond in the center of town (Figure 1). The complex includes a highly rated, comfortable dormitory with a cafeteria and café. It also features classrooms and laboratories for research and training. What it did not have, in 1991, was anything like a computer laboratory. The original statement of work provided for establishment of such a lab (in Phase II alluded to above). Initially, the plan was simply to use wet-lab space. This entailed moving some lobster tanks and putting boards over lab sinks to accommodate desktop personal computers.

Figure 1. The Marine Biological Laboratory in Woods Hole, Massachusetts.

2.3. MBL Short Course Faculty

Don engaged Daniel R. Masys M.D., Director of NLM's Lister Hill National Center for Biomedical Communications, and David Lipman M.D., Chief of NLM's National Center for Biotechnology Information, as faculty. Don recruited Homer Warner M.D., Ph.D., Chair of the Department of Medical Informatics at the University of Utah, as course director. Homer, in turn, brought Peter Haug M.D., from Utah and Paul Clayton Ph.D., previously from Utah but then Director of the Center for Medical Informatics at Columbia University; Paul brought Robert Sideli M.D., from Columbia. Together, they provided good domain coverage for what were, at the time, the major themes in medical informatics: clinical information systems, decision support systems, library databases, and genetic sequencing.

2.4. MBL Short Course Curriculum

According to faculty involved in the initial course offering, very little advanced planning of the actual lectures had occurred (Figure 2). After an initial rocky start, the students were granted their request for a course syllabus, which became the guide for development of subsequent course materials [4]. Evaluations were generally good, with many

comments about the need for and appreciation of structured materials [5]. Afterward, the annual report provided this summary:

> "The objective of the course is to train individuals in the applications of computer and information science in medicine. The training consists of computer-assisted learning, retrieving and organizing information from computerized databases, the application of medical informatics tools to the critical appraisal of literature and associated statistical software packages, hospital-and office-based information systems, and electronic communications. Students build and use a knowledge base for an expert system, and work with software for analysis of biological sequence data. Students also access the broad range of published scientific literature using NLM's Grateful Med. Lectures alternate with hands-on experience" [6].

Monday, June 1
Don Lindberg: Access to Medical Literature and Factual Databases; Grateful Med; COACH; Unified Medical Language System
Dan Masys: Computer Networks: Past, Present, Future; Computer Applications for Health Professions Education

Tuesday, June 2
David Lipman: Access to Protein and Genetic Databases
Dan Masys: Introduction to Database Design; Database Workshop

Wednesday, June 3
Paul Clayton: Integrated Academic Information Management Systems (IAIMS) Overview; Principles of Controlled Vocabulary
Robert Sideli: IAIMS Demonstration; Clinical Information Systems; Data Modeling; Database Design

Thursday, June 4
Homer Warner and Peter Haug: Demonstration and Experience of an Expert System; Analyze Patient Database for Statistics for an Expert System; Work with an Expert System

Friday, June 5
Homer Warner and Peter Haug: Use Skills Learned the Previous Day to Build an Expert System

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Figure 2. Lectures for the first session of the course, June, 1992.

3. Early Years: 1993-1998

3.1. Evolution of the NLM Informatics Short Course

Don took the student evaluations to heart and tapped Dan Masys and NLM Computer Science Branch Chief Lawrence ("Larry") C. Kingsland III Ph.D., to pull together reading materials on the course topics and assemble them into 30 black binders for the students. As a result, the second and subsequent years went much more smoothly. The course continued to be held in a classroom for didactic sessions and the wet lab for hands-on exercises. The lab had 15 personal computers, roughly half Macintoshes and half

Windows-based personal computers. Students were paired up – usually one librarian and one physician to each machine [7].

3.2. MBL Short Course Faculty Progression

Homer Warner continued as nominal course director, but the selection of lecturers and lecture topics was left to Dan Masys and Paul Clayton. Most faculty were re-invited each year. Few declined the opportunity to spend a week participating in lectures with fellow leaders in the field, socializing with informatics friends, and enjoying scenic Woods Hole. As word of the course spread, informaticians and former students alike began asking Homer, Dan, Paul and Don to invite them to be on the faculty. Dan retired from NLM in 1994 to move to the University of California-San Diego. He therefore became eligible to serve as course director; Don signed him on immediately.

Figure 3. Cathy Norton, Director of the Library at Marine Biological Laboratory and Woods Hole Oceanographic Institute.

Figure 4. David Remsen teaching squid neuroanatomy to students in the MBL Marine Resources Center.

While the faculty presented most of the lectures and hands-on tutorial sessions, it was the MBL staff who really made the course function coherently. Cathy Norton was quickly recognized as the key to the entire operation: smart, funny, engaging, and knowledgeable. All who knew her would agree that she was larger than life (Figure 3). Cathy also involved David Remsen, who helped teach technical classes and led tours of the Marine Resources Center, handing live squid, sea urchins and horseshoe crabs to the students (Figure 4) while he explained how studies of their biology had led to Nobel prizes for MBL researchers[2]. Cathy's duties as a justice of the peace provided her with many stories with which to regale the students. She performed marriage ceremonies for several MBL short course faculty (myself included) and renewed vows for one of the students and his very surprised wife. Cathy was nevertheless a librarian at heart, and by

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[2] Over the past 100 years, Nobel prizes have been awarded to 59 researchers with connection to the MBL.

1994 she had become the director of the MBL/WHOI Library. The informatics course was a pet project, to which she devoted enormous energy, personally seeing to the care and comfort of all faculty and students. She was the quintessential hostess and manager. The 900 MBL Short Course students she oversaw undoubtedly remember her well. She continued in her leadership role as Principal Investigator on the NLM Informatics Short Course grant until 2011, when she retired from the MBL. Sadly, she passed away in 2014. She has left indelible marks on the course and all who were involved in it.

Many other MBL staff contributed to the success of the course, ranging from travel and accommodation logistics to technical support and leading hands-on laboratory sessions, including Diane Rielinger M.S., M.L.I.S. (who took over as course principal investigator), John Furfey M.L.S. and Jennifer Walton M.L.I.S.

3.3. NLM Informatics Short Course Topics

The subject matter of the course evolved annually, based on contemporarily important and popular topics. Faculty were added to cover the additional topics, but there was no formal, longstanding syllabus. Rather, the NLM Informatics Short Course was a survey curriculum designed to expose students to general areas and provide sufficient depth to challenge them. It taught students that there was much more to know. As a way of providing some coherence, Dan Masys introduced the idea of a theme for the week and initially chose Alpha-1 Antitrypsin Deficiency, since it had known genetics (including a gene sequence), a serious but treatable clinical presentation, a good differential diagnosis, and easily accessible information in various databases and online resources [5]. Individual faculty embraced this guidance to varying degrees. As described below, the course content became more varied and more intense over the ensuing quarter-century.

Dr. Lindberg usually provided high-level context for the course, presiding over the welcome session, usually the evening before the first day of classes. His introductory comments encouraged students to interact with faculty and each other - in and out of class. He told them not to leave at the end of the week with any burning questions unanswered. He also provided lectures on various topics, ranging from bioinformatics to national policy. He usually presided over the closing session on the last day and made sure that all those questions did get answered. But most of all, he was available during the week to the students before, between and after classes, and at meals. Students were thrilled to share stories and pick the brain of someone who was a legend in his own time and Director of the National Library of Medicine.

4. 1999-2013

4.1. Doubling Down on the NLM Informatics Short Course

As popularity of the course grew, Don decided in 1999 to move from one session per year to two, each with 30 students. Dan Masys then asked for help with directing the course, and in the tradition of "see one, do one, teach one", I was added to the faculty for the new fall course and became its director the following year. Dan continued as director of the spring course until 2005, when he moved to Vanderbilt University. I remained course director through 2015, with help in some years from Clement McDonald M.D.

(Lister Hill Center Director) and Joyce Mitchell Ph.D. (Chair of Biomedical Informatics at the University of Utah).

The shared workstations and paper-based materials gave way to individual laptops (Windows-based or Macs), and the class moved out of the lab to a large, airy room in a building called the Little Club, situated on Water Street, next to the WHOI pier. It was not unusual for class to be interrupted by large research vessels coming to dock in full view of the class. During inclement weather, waves added excitement, breaking on (but not through) the windows.

4.2. Continued Changes to MBL Short Course Contents

Lecture topics continued to evolve (see Figures 5 and 6). The disease-of-the-week changed to hereditary hemochromatosis, with an elaborate patient case that included medical history, family history, physical findings, laboratory results and medications, which many of the faculty worked into their lectures. Dan added a "Vanderbilt Day" to

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Monday, June 1
Jim Cimino: What is Informatics?; Principles of Database Design
Joyce Mitchell: Bioinformatics
Stephen Phillips and Victor Cid: Disaster Informatics
MBL Team (Evening): Managing Data with Drupal; Twitter

Tuesday, June 2
Jim Cimino: Principles of Controlled Terminology
Mike Ackerman: Imaging Informatics; Telemedicine
MBL Team (Evening): Project Time

Wednesday, June 3
Ed Hammond: Clinical Information Systems I
Clem McDonald: Clinical Information Systems II
Kathy Canese: NCBI, Pubmed & More
MBL Team (Evening): Optional Project Time

Thursday, June 4
Rita Kukafka: Public Health Informatics
Alexa McCray: Consumer Informatics
Sue Bakken: Decision Analytic Methods for Evidence Based Practice
Kevin Johnson: Personal Health Records
MBL Team (Evening): Project Time

Friday, June 5
Chris Cimino: Education Informatics
Kevin Johnson: Computer-Based Physician Order Entry
Joan Ash: Evaluation
Larry Kingsland: The Internet: Reflections on What's Coming

Saturday, June 6
Don Lindberg: Current Issues
Students: Project Presentations

Figure 5. Lectures for the spring 2009 session of the course.

Monday, September 16
Joyce Mitchell: What is Biomedical Informatics?
John Hurdle: Major Biomedical Informatics Methods; Clinical Informatics
Joan Ash: Unintended Consequences of Electronic Health Record (EHR) Adoption;
    Evening workshop

Tuesday, September 17
Guilherme Del Fiol: Vocabularies and Terminologies
Charlene Weir: Human Computer Interactions and Issues
Les Lenert: Meaningful use of EHRs
Marcelo Fiszman: Natural Language processing at NLM and Semantic Medline;
    Semantic Medline Evening workshop

Wednesday, September 18
Catherine Staes: Population and Public Health Informatics
George Demiris: Social media and Consumer health informatics
Guilherme Del Fiol: Knowledge Management and Infobuttons

Thursday, September 19
Paul Harris: Clinical and Translational Research informatics
George Demiris: Telehealth and Mobile Devices
Joyce Mitchell: Genetics and Genomics
Dmitry Kondrashov: Mathematical Modeling; Mathematical Modeling Evening
Workshop

Friday, September 20
Kevin Johnson: Biomedical Data Visualization and Interpretation
Ken Kawamoto: Clinical Decision Support, Computer-Based Physician Order
    entry and Quality
Faculty: Ethics and Biomedical Informatics (lunch discussion)
Charlene Weir: Evaluation Issues in Biomedical Informatics
Don Lindberg: Disasters and Informatics

Saturday, September 21
Don Lindberg: Research Issues in Biomedical Informatics

Figure 6. Lectures for the fall 2013 session of the course.

the spring session that included informatics faculty from Vanderbilt to talk about end-to-end informatics development at the enterprise level. When Dan stepped down as course co-director and moved to Vanderbilt, he was able to return in the more relaxed role of faculty member when I continued the Vanderbilt Day tradition.

4.3. MBL Short Course Student Projects

The notion of hands-on laboratories continued to be a mainstay of the course. The admissions process became more formal, with applicants being evaluated for prior computing skills. Applicants were selected who seemed to have the basic skills needed to keep up with the laboratory exercises, and the exercises became more sophisticated. Where early students were learning about PowerPoint, Excel, and HTML, later students were learning about personal databases, publishing web sites, and integrating the two.

Students were grouped into teams to develop projects together, allowing less technically confident students to learn from more advanced users.

Eventually, the course began to schedule the didactic lectures during the day and the laboratory sessions as evening workshops. We began to integrate the daytime topics into the projects. In the spring of 2009, Steven Phillips M.D. (NLM Associate Director) joined the faculty. For several years, he gave a lecture on Disaster Informatics that included activities and research programs in the NLM's Disaster Information Management Research Center (DMIRC). This inspired the MBL staff to alter the evening project to be development of web sites for disaster management that made use of DIMIRC's tools, including patient locators and hospital capacity trackers. The "disaster" they chose to prepare for was the Zombie Apocalypse. MBL Staff enthusiasm gave way the final evening to them showing up as zombies to attack the class.

As fun as the zombie theme was, it was a little far afield of the daytime lecture themes. However, the disease-of-the-week case was a patient who acquired paralytic shellfish poisoning from eating at a local seafood restaurant, so we decided to use a red tide outbreak as our disaster. What we didn't know was that there was a small red tide outbreak on Cape Cod that week. When area residents started searching the web for information, they happened upon the students' websites. This caused quite a bit of consternation because the sites described a fictitious scenario in which hospitals were filling up with victims. Confusion ensued as people started calling news organizations to ask why they were covering up the outbreak, leading those organizations to contact MBL leadership who was, of course, totally unaware of our students' projects and unable to explain why MBL websites were publishing misleading information. It all got straightened out, with students' sites being placed behind the MBL firewall, but for a while it was reminiscent of Orson Welles's 1938 War of the Worlds radio broadcast.

4.4. MBL Short Course Social Events

No description of the course would be complete without commenting on the social aspects of the week. In addition to the opening reception and meals and break times, students and faculty alike often found the energy for some decompression time after the evening workshops. This usually entailed commandeering several of the large round tables at the Captain Kidd, a local watering hole that was literally a stone's throw from the Little Club. A common pattern was for there to be a small gathering of a few faculty and students early in the week, with growing numbers each evening, sometimes achieving perfect attendance by the last night. Another treat was a traditional New England clambake one evening. Very few actual clams were involved. Steamed Maine lobsters were the main attraction. Many students over the years added learning how to eat one to their list of educational experiences for the week. Although Don did not usually appear at the "The Kidd", he and Mary were reliable participants for other activities.

5. NLM Informatics Short Course 2014-2017

As the MBL's contract neared its end, the NLM was required to openly compete renewal bids. This timing coincided with a change in leadership at MBL. For reasons that were never made clear to NLM, the MBL decided not to submit a proposal for renewal. Several other organizations did, however. Michael J. Ackerman Ph.D. (Chief of NLM's Office of High Performance Computing and Communications), Kathel Dunn M.L.I.S., Ph.D.

(NLM's Associate Fellowship Program Coordinator) and I made several site visits to consider a replacement.

The clear winner was Augusta University, which offered its Brasstown Resort and Spa located in Young Harris, Georgia, as the site for the class. While a very different setting than Woods Hole, it lived up to its name in terms of comfort. All rooms were single occupancy, with televisions – luxuries not previously available at the MBL.

The real appeal, however, were the staff and educational facilities. Brenda Seago M.L.S., M.S., Ph.D. became the new contract Principal Investigator. She was (and, at the time of this writing, remains) Director of Libraries at Augusta University, serving ten colleges and schools with almost 10,000 students. She and her staff (including project leader Kathy Davies M.L.S.) had extensive experience with development of a number of training programs, making use of the latest educational methods and technologies. Added to this was the auditorium at the Brasstown Resort with comfortable chairs, generous desk space and excellent acoustics – all things not present in the Little Club.

Monday, September 11
Bill Hersh: What is Biomedical Informatics?
Hugo Campos: From Engagement to Autonomy: Leveraging Data and Technology
Daniel Fabbri: Security and Privacy
Paul Harris: Data Management; Data Management Implementation Using REDCap (Evening Session)

Tuesday, September 12
Don Lindberg: Genetics, Genomics, and Why We Care
Elmer Bernstam: Precision Medicine from an Informatics Perspective
Kathy Davies: NLM Resources
Eric Sayers: Practical Bioinformatics for the Clinic
Kathy Davies, Eric Sayers: Exercises in Knowledge Retrieval (Evening Session)

Wednesday, September 13
Rebecca Schnall: Consumer Health Informatics; mHealth Technology
Randy Miller: Ethical Issues Related to Research, Evaluation, Publication, and Implementation in Biomedical Informatics (Evening Session)

Thursday, September 14
Michael Ackerman: Imaging Informatics
Zhiyong Lu: Biomedical Data and Information Visualization
Karen Rheuban: Using Telehealth to Increase Multi-Disciplinary Collaboration and Improve Health Care Outcomes
Jessica Schwind; Public Health Informatics
Dmitry Kondrashov: Mathematical Modeling with Clinical Decision Support

Friday, September 15
Olivier Bodenreider: Controlled Vocabularies and Semantic Standards
Jeremy Warner: EHRs, APIs, and Apps
Dina Demner-Fushman: Natural Language Processing Support for Clinical Tasks
Kim Unertl: Organizational Issues in Biomedical Informatics

Saturday, September 16
Patti Brennan: Anticipating the 3rd Century of the National Library of Medicine

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Figure 7. Lectures for the final session of the course in the fall of 2017.

After 17 years with the course, I stepped down as director after the Fall of 2015. Mike Ackerman took over in 2016 and Dina Demner-Fushman Ph.D. (an investigator in the Biomedical Informatics Branch, of NLM's Lister Hill Center) joined as co-director for the 2017 sessions. Although the structure of the course and many of the topics remained basically the same (minus the clambake), the faculty roster underwent major revision as many new, but nonetheless distinguished informaticians were brought in (Figure 7).

By this time, Don had retired from NLM but he and Mary continued to participate in the course. Don lectured on genomics and general research issues. Attendees were still thrilled to have him there, along with the new NLM director, Patti F. Brennan R.N., Ph.D.

A bigger change was to come, though. The "Georgia Course" as anyone not from Georgia came to call it, was undeniably a huge success. But the need to reach a broader audience and the advent of improved, inexpensive teleconferencing technologies, meant the days of intense, in-person training with a small student body (30) and a large faculty (20 or more), along with the attendant travel costs, were numbered. The NLM did not activate the final contract year of the course. It regrouped to consider how best to use limited resources to effect a broader impact [8].

6. "The Woods Hole Experience" in Print

Descriptions of the course have appeared in the peer-reviewed medical literature over the years. Some briefly mention its existence [9-11]. More details can be found in two evaluation reports of the fall 2000 course by A. Cimino (née Brummitt) and the spring 2005 course by Bridges and colleagues, respectively [12-13]. Correlating the descriptions herein with the descriptions from these two reports provides a clear picture of how the course evolved over time.

With regard to course evaluations, Bennett-McNew and Ragon reported their informal survey results from Fall 2005 participants [13]. They did not report numbers of respondents, but one can infer that nine librarians responded. The authors included anecdotal comments and in summary concluded that the course had a notable (presumably positive) impact on all respondents. Many reported a lasting influence on their careers.

Patel and colleagues conducted a more comprehensive evaluation, using quantitative and qualitative techniques [14]. Twenty-nine participants from the Spring 2002 course completed pre- and post-course surveys and participated in interviews. In addition, a randomly selected half of the 360 participants from the 1992-2001 courses received questionnaires by mail.

The course was highly rated by all survey respondents. They were especially impressed by the quality of the speakers, networking opportunities, the learning environment, and their ability to acquire specific knowledge. Interviews conducted four months after the course found that all students had become involved in new informatics activities. The mailed questionnaire results indicated that a high percentage of the 121 respondents had become involved in making strategic healthcare technology-related decisions. They had engaged in training others in the use of information technologies, and had recommended, specified or approved new information systems at their institutions. Respondents also reported a wide variety of long-acting positive influences on their knowledge of informatics. The survey authors summarized their findings thusly:

"The majority of the participants who responded to the questionnaire have since become effective agents of change in their institutions in the area of medical informatics, perhaps as a direct result of these positive experiences or as a result of a combination of other factors, in addition to the course" [14].

7. Discussion

In a way, the National Library of Medicine's Biomedical Informatics Short Course was a metaphor for the larger academic field. Over time, the topics became more technical, more varied, increasingly drew on related fields, and encompassed greater breadth across the spectrum of translational science. The course employed increasingly sophisticated information technology, including teleconferencing and the resources of the World Wide Web. The faculty list reads like a Who's Who of biomedical informatics. The diversity of the students was impressive - coming from all 50 U.S. states and many foreign nations. The scope reflected both intended users and beneficiaries of informatics.

Don Lindberg's contributions to the course ranged from its highest to its lowest levels. He conceived the idea of NLM workshop sponsorship with the goal of reaching out to, and often creating anew informatics-related change agents. This encompassed all healthcare roles – not just patient care and librarianship, but policy makers, payors, and developers and vendors of EHRs and decision support systems. Dr. Lindberg constantly provided input in determining faculty participants, topics, and student admission criteria. He also contributed to the actual teaching in diverse ways, even stepping in to fill gaps due to a rare faculty absence. Finally, he was a key participant in the informal networking and interpersonal socializing among students, faculty and staff.

I would be remiss if I did not acknowledge Mary Lindberg's contributions as well. She has probably sat through more informatics lectures than anyone in history, except for Don. She contributed greatly to discussions during and between classes, with her knowledge of informatics, informaticians, nursing and palliative care. When it came to networking and social aspects of the course, she participated equally with Don.

In the end, one cannot make a comprehensive accounting of the impact of the NLM Informatics Short Course project. Over the years, it brought together 1,350 students and close to 100 faculty who then collectively contributed to shaping the unique professional community that is biomedical informatics. The faculty learned as often as the students. They brought new experiences and ideas back to their home institutions. Doing so enhanced their own educational programs and further extended networks of collaborators.

The course was an intense experience for all who participated. Many students expressed a desire for a second course – until they were told what such a course would require tuition without NLM support. There is no question that the course was expensive and no question that its value justified NLM's support. It is likely that the expense of the NLM Informatics Short Course has been paid back in terms of its impact on the field. The NLM Informatics Short Course led to more rapid and widespread adoption of informatics technologies and deeper investment of participants' institutions in informatics infrastructure and offerings. The limited evidence from published papers and anecdotal experiences suggest that this has occurred.

8. Conclusion

The "Woods Hole Course" was an amazing experience for those fortunate enough to participate in it. We can all be grateful that Dr. Lindberg made it happen. Its faculty and students have been inspired to change their institutions and their field for the better. Many participants had their burning questions answered at Woods Hole and at Young Harris. They learned enough to go on to ask the next round of burning questions during their careers.

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NLM's Sponsorship of Research in Biomedical Informatics (1985-2016)

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Abstract. The U.S. National Library of Medicine's (NLM) funding for biomedical informatics research in the 1980s and 1990s focused on clinical decision support systems, which were also the focus of research for Donald A.B. Lindberg M.D. prior to becoming NLM's director. The portfolio of projects expanded over the years. At NLM, Dr. Lindberg supported various large infrastructure programs that enabled biomedical informatics research, as well as investigator-initiated research projects that increasingly included biotechnology/bioinformatics and health services research. The authors review NLM's sponsorship of research during Dr. Lindberg's tenure as its Director. NLM's funding significantly increased in the 2000's and beyond. Authors report an analysis of R01 topics from 1985-2016 using data from NIH RePORTER. Dr. Lindberg's legacy for biomedical informatics research is reflected by the research NLM supported under his leadership. The number of R01s remained steady over the years, but the funds provided within awards increased over time. A significant amount of NLM funds listed in RePORTER went into various types of infrastructure projects that laid a solid foundation for biomedical informatics research over multiple decades.

Keywords. U.S. National Library of Medicine, Donald A.B. Lindberg, Biomedical informatics, Informatics Research Funding

1. Introduction

Research in biomedical informatics is the cornerstone for advances in the way computers and systems can impact the health of millions of people. In addition to stimulating a sea-change in biomedical informatics research during his tenure at the U.S. National Library of Medicine (NLM), Donald A.B. Lindberg M.D. contributed to a significant increase in biomedical research in general. He enabled world-wide free-of-charge dissemination of scientific peer-reviewed abstracts from the biomedical literature through PubMed [1]. Under his leadership, the NLM also made available numerous other databases and knowledge bases, which serve as foundations for entire fields such as toxicology and molecular biology. His experience as a biomedical researcher helped him understand the importance of foundational informatics research and development [2].

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During Dr. Lindberg's tenure, NLM developed a significant infrastructure that engaged the extramural research community. From his own experience in conducting research at an intersection of disciplines, and by assembling a talented team that could bring projects to the finish line, Dr. Lindberg enabled generations of investigators to explore a wide range of biomedical informatics research topics with funding from NLM.

This chapter briefly reviews Dr. Lindberg's legacy as a pioneer in pathology informatics research to provide context for the focus on decision support systems in his early years at NLM, and his work on hospital information systems that influenced his role as a critical enabler for other investigators [2]. NLM influenced the fields of biomedical informatics and library science in numerous ways. It implemented services and tools that helped investigators worldwide accelerate their research. This chapter initially highlights aspects of Dr. Lindberg's own research before he became NLM's director. To provide context about the environment in which NLM investigator initiated R01s evolved over the years, the chapter also cites major NLM programs that impacted the biomedical research community, such as PubMed, the National Center for Biotechnology Information (NCBI) portfolio of biomedical databases, and ClinicalTrials.gov. Finally, the authors present a novel analysis of NLM's funding trends for extramural research from 1985-2016.

2. Research in clinical decision support systems

Dr. Lindberg had hands-on experience in computer applications in a hospital setting long before he was selected to lead NLM [2]. A pathologist by training, Dr. Lindberg spent his research years developing new algorithms and tools for the analysis of various types of clinical pathology data. One of his first indexed articles, published in 1963, dealt with the automatic measurement and processing of microbiology data [3]. In 1964, he published an article that went beyond pathology, entitled "Computer Generated Hospital Diagnosis File" [4]. A few years later he discussed computer-assisted collection, evaluation, and transmission of Hospital Laboratory Data [5]. His 1968 book, entitled "The Computer and Medical Care," targeting an audience of readers who understood hospitals but did not necessarily understand computers, was reviewed in the journal Medical Care [6]. The reviewer pointed out that "Dr. Lindberg details a working data system using punched cards and teletype printers" and that he addressed quality improvement: "The ability of the computer to prevent and detect errors by improving quality control in the hospital laboratory is documented." The review concludes "this is a most worthwhile book… Dr. Lindberg is recognized as a leader in his field, and he has made a real contribution in making his work more readily available to those wishing to know more about the computer and medical care" [6].

As mentioned in the book review, Dr. Lindberg's contributions were not limited to pathology. In 1968, he published one of the first articles on the automated analysis of electrocardiograms EKGs [7]. It required an additional 20 years for automated EKG analysis to become mainstream in medicine: only in 1988 did Medicare approve reimbursement for automated EKG analysis [8]. Coincidentally, this was the same year in which, given the growing importance of molecular biology and databases, the U.S. National Center for Biotechnology Information (NCBI) was founded under Dr. Lindberg's tenure at NLM [9].

Before Dr. Lindberg was sworn as NLM Director in 1984, he had expanded his research portfolio outside of pathology. He published a paper on a computer-based drug

information system in 1974 [10]. His last major contribution before becoming NLM's director was an expert system named AI/RHEUM, designed to serve as a consultant system for rheumatology [2]. Having spent over 20 years as a pioneer in a field that was relatively unknown at the time probably helped Dr. Lindberg appreciate the importance of extramural funding and the impact the U.S. National Institutes of Health (NIH) could have for biomedical informatics.

3. NLM director's support for research infrastructure

In 2010, Dr. Lindberg published an overview of NLM's history [11]. NLM's direct contribution to extramural research came from the different initiatives outlined below.

3.1. Infrastructure for biomedical research

The impact that NLM had on biomedical research and healthcare is reflected in the growth of the scientific literature itself. By making abstracts from that expanding literature freely available worldwide, NLM increased its international standing and relevance [1]. Early on, when the Internet did not exist and library collections consisted of paper-based books and journals, networked academic medical centers were not common. Integrated Academic Information Management Systems (IAIMS) was a concept created before Dr. Lindberg became NLM director but was realized during his tenure [12-13]. In this initiative, NLM played a central role in information networked systems. The fact that this seems logical and unsurprising today is a testament on how the idea really took flight. The significance is that the whole biomedical community started to become more familiar with computers. MEDLINE, the largest database of biomedical literature in the world, was popularized by the application Grateful Med, a search engine for MEDLINE, which made it easy for clinicians and researchers to browse the scientific literature to find articles that would improve care or accelerate their research [14-15].

Another application launched under Dr. Lindberg's tenure was ClinicalTrials.gov, which helped with registration of clinical trials and with displaying information about their eligibility criteria, study design, etc. [16]. While several applications relating to publications or studies were launched, additional sources of data in NCBI were growing fast, and the center became a critical source of information for a growing molecular biology research community around the world [17]. The Internet-based PubMed application serves as a portal and search engine and is undoubtedly the most popular application in the history of NLM, the NIH, or any other resource for biomedical researchers [18]. Clinicians and researchers can support their decision making based on articles they find on PubMed. All major health sciences breakthroughs are documented in the pages of journals indexed for PubMed. Still under Dr. Lindberg's directorship, NLM launched PubMed Central, where full articles are deposited and made freely available to anyone [19].

In addition to infrastructure that benefitted biomedical researchers worldwide, the NLM supported infrastructure that specifically enabled the acceleration of biomedical informatics research.

3.2. Infrastructure for biomedical informatics research

NLM utilized both intramural and extramural researchers to build a framework that would impact research nationwide [20]. The NLM's Unified Medical Language System (UMLS) project is documented elsewhere in this book [21]. The project's goal was to enable interoperability among systems by putting into place shared vocabularies and standards. Another important Lindberg infrastructure initiative was NLM's involvement in the interagency High Performance Computing (HPC) and Communications Program (HPCC) [21-22]. The development of an "information superhighway" for biomedical data was also among NLM's flagship initiatives, where again the extramural scientific community was engaged in developing new applications that would move data faster into facilities supported by the NLM where data could be processed and analyzed. This included research in telemedicine, electronic health record systems, and virtual reality in many institutions across the country. Taken together, these research infrastructure efforts were prescient of the acclaimed, contemporary FAIR principle: make data and tools findable, accessible, interoperable and reusable [23].

4. NLM's direct funding for biomedical informatics research

In a NLM Board of Regents meeting in 2014, Valerie Florance Ph.D., Director of Extramural Programs, reviewed NLM's research funding from 1984-2014 [24]. Florance suggested "By 1985, 50 percent of the research grants NLM awarded had medical decision support as a focus." Florance also noted NLM's long-range plans expanded the scope of its grant programs and recent plans emphasized biotechnology as well as the need for research on fundamental issues and methods in medical informatics. She added that "By 1998, 44 percent of grants were for biotechnology research."

NLM's 2000 Long Range Plan further "expanded research to include consumer health information, patient-specific data, and access to knowledge-based information." Grants became larger during the first decade of the 21st century, Florance noted. She explained success rates have gone "up and down," and NLM, which was considered the only supporter of informatics at NIH had company. NIH programs such as Big Data to Knowledge (BD2K) and other NIH institutes sponsored biomedical informatics research.

To provide insightful details regarding funded NLM extramural R01 projects, the authors analyzed data that NIH makes publicly available. The analysis collected the NLM-funded projects accessible through the NIH RePORTER API V2.0 released in 2021 with valid new project cost and keyword indexing terms information from Fiscal Year (FY) 1985 (the earliest year available in NIH RePORTER) to FY 2016, as demonstrated in Figure 1A (all years mentioned in the rest of this section are FYs unless otherwise stated) [25-26]. In general, the number of funded NLM R01 projects remained around 13, while the overall number of NLM projects increased. On the other hand, the average project cost for an R01 increased steadily, while the overall average cost increased more sharply after 2007 (Figure 1B).
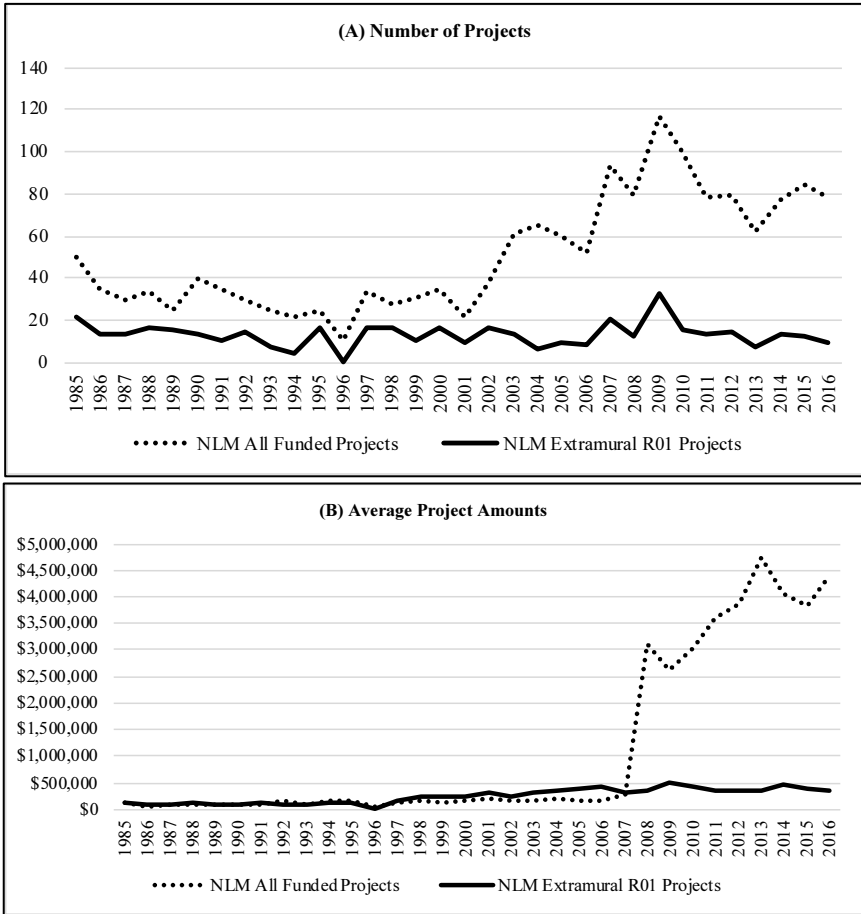
Figure 1. Statistics of NLM projects from 1985 to 2016. **(A)** Number of projects. **(B)** Average project amounts. The NLM All Funded Projects included both extramural and intramural projects.

The number of project keyword indexing terms, as shown in Figure 2, increased significantly after 2007 because of a system change from the Computer Retrieval of Information on Scientific Projects (CRISP) system to the Research, Condition, and Disease Categorization (RCDC) process, as described below [27-29]:

"Beginning with projects funded in FY 2008, project terms are concepts derived by mining the text of a project's title, abstract, specific aims, and investigator's stated public health relevance. For projects funded in fiscal years prior to 2008, the project terms in RePORTER are the same terms used in the NIH CRISP system that RePORTER replaces. See the Research, Condition, and Disease Categorization Process for a complete description of this text mining process."

The authors split the years into six periods for further project indexing term analysis (the areas split by the vertical lines in Figure 2). Authors excluded 1996 (in which no terms were provided for any project in RePORTER) and included 1985 in the first period

(because the total number of years, after excluding 1996, is not divisible by five). The project indexing terms before and after the system change are not comparable [29]:

"Term searches that span fiscal years before and after 2008 will not be comparable. There is no simple and direct association between the CRISP terms used prior to 2008 and the project concepts derived through text mining in 2008 and later years."

Therefore, all of the subsequent analysis results of the last two periods (i.e., "2007-2011" and "2012-2016") are also not directly comparable with the results from earlier periods.
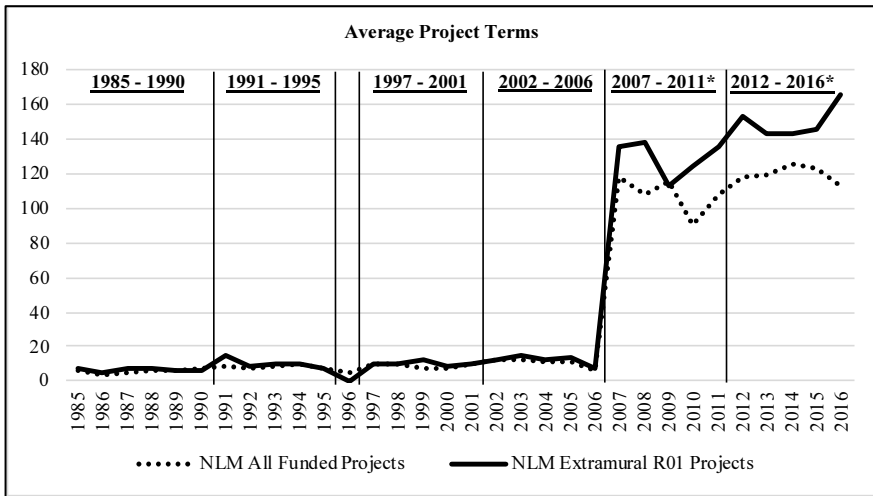
Figure 2. Average project terms from 1985 to 2016, split into six five-year periods (excluding 1996, and the first period contains six years). The last two periods ("2007 – 2011" and "2012 – 2016", marked with an asterisk symbol "*") contain project terms collected using a new system, thus having a significantly higher number of average project terms [29].

For each period shown in Figure 2, the analysis involved Principal Component Analysis (PCA) with 95% variance coverage and identified the top three Principal Components (PCs) [30-31]. Then, the analysis progressed to include Expectation Maximization (EM) clustering based on K-Means algorithm [32-33]. The details of the approach are as follows: the authors initially set the K (i.e., number of clusters) to one, split the data into ten folds, and then performed EM for ten times to compute the average log-likelihood of the clustering results in these ten folds [34]. Then, the analysis increased K by one and repeated the above process, to see if the log-likelihood increased. This increment of K continued until the log-likelihood decreased. The largest K before the decreasing log-likelihood was used as the final number of clusters. Using the method above, authors clustered the projects based on the three PCs. In all periods the algorithm generated $K = 2$ clusters, while in the "2007 – 2011" period there are $K = 5$ clusters being created. In the 3-Dimensional PC space, the projects in the first four periods are sparser while the ones in the last two periods are denser, reflecting the difference after the system change. Authors used the Java-based Weka library to conduct the analysis [35].

The analysis further extracted the top ten project indexing terms in each cluster of projects for each period based on their frequency (Table 1 and Table 2). Again, the set of project terms in the first four periods are different from the ones in the last two periods because of the system change. To compare the results across all periods, the authors manually reviewed and evaluated the project terms. Artificial Intelligence (AI-vertically-shaded in Table 1 and Table 2) was mentioned frequently between 1985-1995, and then less mentioned between 1997-2011, and finally fell out of the top ten. Meanwhile, genomics (horizontally shaded in Table 1 and Table 2) were frequently mentioned from 1985 to 1990, and then became prevalent again from 2007 to 2011. Also, "data", "base", "databases", and "data bases" were all valid project terms in the new system (i.e., in the last two periods), nevertheless "data" and "base" appear more frequently than the other two.

Table 1. Top one to five project indexing terms in each cluster, as they appear in NIH RePORTER. Each row represents a cluster of projects in the corresponding period, and the project terms were ranked based on their frequency. The vertically shaded ones are related to Artificial Intelligence (AI), and the horizontally-shaded ones are related to genomics. The results of the last two periods ("*") have different set of project terms because of the system change.

Period	Top 1	Top 2	Top 3	Top 4	Top 5
1985-1990	information systems	literature survey	computer assisted medical decision making	artificial intelligence	computer system design /evaluation
	history of life science	books	monograph	physicians	united states
1991-1995	computer assisted medical decision making	history of life science	artificial intelligence	computer program /software	information systems
	history of life science	medicine	publications	data collection	physicians
1997-2001	human data	computer system design /evaluation	information retrieval	information system	computer program /software
	clinical research	computer assisted medical decision making	computer system design /evaluation	health services research tag	human subject
2002-2006	clinical research	computer program /software	computer system design /evaluation	human subject	human data
	clinical research	health services research tag	health care service evaluation	behavioral /social science research tag	computer assisted patient care
2007-2011*	data	research	base	methods	tool
	base	clinical	data	research	improved
	computational modeling	computational models	computational simulation	computer based models	computer based simulation
	base	data	genome wide analysis	genome wide association	genome wide association scan
	base	computers	design	designing	face
2012-2016*	data	base	patients	research	improved
	data	novel	base	methods	disease

Table 2. Top six to ten project indexing terms in each cluster. The notations are the same as that of Table 1.

Period	Top 6	Top 7	Top 8	Top 9	Top 10
1985-1990	computer assisted diagnosis	nucleic acid sequence	information retrieval	medical education	physicians
	epidemiology	health care quality	language translation	british isles	communicable disease control
1991-1995	computer system design /evaluation	human data	human subject	computer assisted diagnosis	computer assisted patient care
	travel	books	culture	united states	racial /ethnic difference
1997-2001	information system analysis	vocabulary development for information system	artificial intelligence	behavioral /social science research tag	history of life science
	internet	behavioral /social science research tag	computer assisted patient care	human data	health care quality
2002-2006	informatics	internet	information system	model design /development	computer human interaction
	human data	human subject	patient care management	biomedical automation	computer assisted medical decision making
2007-2011*	system	loinc axis 4 system	process	testing	modeling
	goals	patients	system	loinc axis 4 system	time
	computer models	computer simulation	computerized modeling	computerized models	computerized simulation
	genome wide association studies	genome wide association study	genome wide screen	genome wide studies	genome-wide identification
	faces	facial	information technology	investments	learning
2012-2016*	methods	address	clinical	system	tool
	disorder	disease/disorder	improved	data set	dataset

A strong emphasis on computer-assisted systems for clinical decision making was clear until 2006, and genome-wide studies constituted a well-defined cluster in 2007-2011.

However, this analysis has limitations because it does not always confirm the findings described in the 2014 NLM Board of Regents minutes [24]. For example, biotechnology terms did not appear frequently until a decade ago, and then only genome-wide terms appeared in one cluster. Disaster preparedness does not feature as a frequent term and health services research does not appear at all after 2007. Spurious terms such as "British Isles" appear in the list of frequent terms, even before an automated term capture system was put in place. This may just be an artifact of selecting only the top ten terms, or of the inclusion of wrong data in RePORTER. As indicated previously, the methods by which terms were assigned for each grant changed in 2007, so comparisons between pre and post-2007 trends are not warranted. The automated project terms assignment also seems not to be discriminating since the most frequent terms include general descriptions such as "data" or "computers."

Nevertheless, the analysis confirms that R01s on certain topics were funded steadily during the decades in which Dr. Lindberg directed NLM, and that from the 2000s onward the amount of research funding increased significantly.

This chapter provides overviews of three decades of NLM funding for research and research infrastructure that involved the extramural community. The impact is palpable not only in terms of continued resources that expanded the depth and scope of the biomedical informatics community. The NLM programs expanded and supported the number of faculty members and trainees in biomedical informatics nationally. The NLM will continue to have a profound impact on the field of biomedical informatics, and Dr. Lindberg's legacy will live on.

Acknowledgements

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The U.S. National Library of Medicine's Impact on Precision and Genomic Medicine

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Abstract. Precision medicine offers the potential to improve health through deeper understandings of the lifestyle, biological, and environmental influences on health. Under Dr. Donald A. B. Lindberg's leadership, the U.S. National Library of Medicine (NLM) has developed the central reference resources for biomedical research and molecular laboratory medicine that enable precision medicine. The hosting and curation of biomedical knowledge repositories and data by NLM enable quality information reachable for providers and researchers throughout the world. NLM has been supporting the innovation of electronic health record systems to implement computability and secondary use for biomedical research, producing the scale of linked health and molecular datasets necessary for precision medicine discovery.

Keywords. Donald A.B. Lindberg, National Library of Medicine, Precision Medicine, Genomics, Electronic Health Records.

1. Introduction: "Scenario 2006"

Thirty-four years ago, Donald A.B. Lindberg M.D., then Director of the U.S. National Library of Medicine (NLM), and L. Thompson Bowles M.D., Ph.D. envisioned the seemingly long-shot "future" of a 2006 response to an unknown exposure [1]. This scenario, included in the cited NLM 1987 Long Range Plan, involved a remote industrial plant in rural Virginia where three workers were exposed to an unknown gas that was used in the 1950s for rocket fuel research. During the rescue, the unknown chemical was rapidly identified by querying the patients' clinical signs and symptoms and gas chromatography testing against public molecular databases. Because the disease was rare, the healthcare providers found treatment guidance rapidly from the few case reports through literature queries. The clinical follow up of the patients was also reported in future studies.

Although this futuristic story was imagined in 1987, it foreshadowed routine medical practice today. Querying NLM-created public databases is now an essential part of research and clinical problem solving. As Dr. Lindberg imagined, patient management presently no longer relies solely on the knowledge "off the top of the physicians' head,"

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but rather on carefully tailored plans based on all available clinical studies and state-of-the-art treatment options. It is notable that Lindberg's earlier scenario not only foreshadowed general usage of reference resources but also collection of 'big data' primary data resources, that would be curated, searchable, and cross-indexed. One might add several other functionally very similar scenarios today, equally supported by the NLM, such as the exposure to an unknown microorganism (e.g., SARS-CoV-2, which was sequenced and tested against known sequences stored in NCBI resources), or mapping of an unknown genetic variant to its pathogenicity interpretation in ClinVar and disease information from the Online Mendelian Inheritance in Man (OMIM) and linked PubMed articles.

2. What is Precision Medicine, and Why Precision Medicine Needed the NLM

Hippocrates said, "It is more important to know what sort of person has a disease than to know what sort of a disease a person has." Physicians have always sought to provide "personalized" medicine to their patients. The dramatic advances in medicine in the 20th and early 21st century brought transformative new tools to the practice of medicine, many driven by mechanistic understandings of disease, such as antibiotics or cancer chemotherapy. The transformative success of antibiotics paired a precise cause of disease with a biologically rational and inferable treatment. This is the essence of "precision medicine" - an approach to disease treatment and prevention that seeks to maximize effectiveness by considering individual variability in genes, molecular and external environment, and lifestyle. Today, the most commonly assayed molecular variation is genomic variation. Indeed, genomic testing is becoming a routine assessment for many diseases, especially cancer, suggesting new treatments for disease, and enabling clinicians to better target therapies to maximize efficacy and reduce toxicity.

Precision medicine as a field is closely related to personalized medicine, individualized medicine, genomic medicine, and other similar terms. What precision medicine specifically adds to these other fields, as highlighted by the 2011 National Academies of Medicine report, is an enhanced knowledge of disease mechanisms and related new taxonomies that incorporate molecular understandings of disease [2]. The latter advances result in more precisely targeted therapies. For these reasons, the authors will focus on "precision medicine" for the rest of this chapter, recognizing that for most purposes, any of the above terms could apply.

The previously cited 1987 Long Range Plan, in Domain 4, proposed a blueprint for implementing Dr. Lindberg's goal to have machine-readable and computable biomedical information, including medical knowledge and health records and the development of the Unified Medical Language System (UMLS) [3]. The Plan listed the important issues and methodologies in medical informatics, such as cognitive processes, medical decision making, the human-machine interface, knowledge representation, knowledge acquisition, and information storage and retrieval.

Under Dr. Lindberg's leadership, the NLM invested in three areas that enabled precision medicine to become a reality and begin to impact care: (a) curation of not just the literature but storage and cataloging of emerging digital data (especially of the genome), (b) electronic health records that supported clinical decision support, and (c) computational tools to link, search, compare, and analyze the resources described above. Collectively, these result in the emergence of "big data" that is minable and accessible.

3. The Importance of Curation and Accessibility

Dr. Lindberg saw the importance of retaining curation as a key function of the NLM, but he knew that curation would evolve [3]. When he became NLM's Director, the Library was perhaps best known for Index Medicus. Online access was provided via MEDLINE, which was accessible optimally at the time by trained medical librarians. During Dr. Lindberg's term, NLM grew to host and curate not just medical literature but a wide array of other types of information, including primary data [3].

NLM's 1987 Long Range Plan envisioned to make information more accessible to health professionals, stating, "One issue NLM should address is that many physicians and other health professionals do not now routinely use computerized information sources such as NLM's in their practices. If the routine use of such information to improve medical care is to become a reality, health professionals must have available better training, education, and practice in electronic data retrieval and manipulation methods" (Domain 3) [1]. Dr. Lindberg had the vision that MEDLINE needed to become democratized beyond a restricted access online system often requiring librarians to a resource that could be used by everyone, including researchers, clinicians, and even the public.

PubMed was released in 1996, setting a paradigm of public data availability and accessibility that would characterize much of the NLM's work during Dr. Lindberg's tenure. PubMed revolutionized clinical and biomedical practice by disseminating primary knowledge and making it accessible to all. Today, it is common for practicing providers and researchers alike to look up studies daily and build their own research projects based on the literature body. Another transformation came with the launch of PubMed Central (PMC) in 2000, which has made millions of full-text research articles free to the public. PMC laid the groundwork and created an expectation for the NIH Public Access Policy, which required the published results of NIH-funded research to be submitted to PubMed Central for public release no later than 12 months after the publication starting in 2008 [4].

The founding of the National Center for Biotechnology Information (NCBI), as detailed elsewhere in this book, represented a pivotal moment in the important role NLM plays in precision medicine [5]. With the creation of NCBI, Dr. Lindberg moved to store and curate data and other types of information, spurred in part by the needs of the Human Genome Project. High throughput genetic and molecule-based microbe identification is also widely adopted in many references and even smaller clinical laboratories.

The NCBI data repositories are a key to the processing and interpretation of clinical genomic testing [6]. Tools such as GenBank, dbSNP, OMIM, and ClinVar are important primary reference sources to decide which genomic regions need to be assayed and how each target should be covered (depending on the physical properties of the variants, such as single nucleotide variance or structural variation). Each of these resources has well defined curation and data models, a common design paradigm, and fast, easily used interfaces that are designed to be accessible to a large variety of audiences. As more and more clinical genomic sequences are generated, these tools have moved from research uses to resources to support clinical care - just as use of PubMed has evolved. For instance, when an individual patient's genome is sequenced, a vast array of variants will be detected, each of which could be benign, a risk factor, or pathogenic for a given disease or enhanced drug interaction. The dbSNP and ClinVar databases provide aggregation of interpretations for pathogenicity linked to diseases. The cross-indexing of

NCBI resources such as dbSNP, OMIM, ClinVar, and PubMed facilitate research and clinical interpretation.

The NCBI also maintains linkage to external resources such as the GWAS Catalog, hosted by the European Molecular Biological Laboratory, and integrates results within its resources. As an analog to PMC for genomics, NCBI's creation of dbGaP provided an important first generally available resource to make individual-level genomic and phenomic data Findable, Accessible, Interoperable, and Reproducible (FAIR) at scale. Data from dbGaP has been used and combined for many new studies by many researchers. For example, Mosley et al. used publicly available data from Atherosclerosis Risk in Communities (ARIC) and the Multi-Ethnic Study of Atherosclerosis (MESA) studies hosted in dbGap (accession: phs000280 and phs000209 respectively) to evaluate the predictive value of an additional polygenic risk score to a clinical risk score for incidence of coronary heart disease [7].

NCBI grew to house other resources such as OMIM, Genetics Home Reference (now called MedlinePlus Genetics), and MedlinePlus. Both OMIM and MedlinePlus Genetics provide informative narrative summaries on Mendelian diseases, their symptoms, causes, and genes. Each of these summative resources is deeply curated and cross-indexed to common vocabularies. These features promote computational interoperability as well as providing accessibility to the web-based user.

The NLM's online repositories of literature and data created a "one-stop-shopping" platform for derivative systems and tools based on the availability and accessibility of vast contents. Examples include Basic Local Alignment Search Tool (BLAST) and the Entrez suite with Application Programming Interfaces (APIs). Similarly, researchers can integrate PubMed queries and MedlinePlus articles into their systems via APIs. Large data sets can be built for artificial intelligence and machine learning, natural language processing, and to support expert systems. For example, many bioinformatics classes use BLAST to compare microbes, such as enterohaemorrhagic Escherichia coli O157:H7 to nonpathogenic E. coli strains, or to search for candidate virulence factors described in an early 2000 study [8]. Similar approaches also were used recently to explore the origins of SARS-CoV-2 [9]. As another example, Tahsin et al. used NCBI APIs to develop a system to extract geographic information from the linked PubMed Central articles for the pathogen sequences on GenBank [10]. Zhang et al. created a literature-derived knowledge graph to identify potential drug-repurposing for COVID-19 treatment [11].

In addition to systems, NLM Long Range Plans recognized the need to train a generation of computational biomedicine researchers [12-13]. The NLM developed a number of programs that made basic and advanced informatics training available to broad audiences of researchers, providers, and other populations through T15 training grants, K awards, and the Biomedical Informatics Short Course at Woods Hole/Georgia.

4. Electronic Health Records - a Real World Platform to Enable and Implement Precision Medicine

Electronic health records (EHRs) are such a fundamental part of all medical practice today that it is hard to imagine a world without them. Nevertheless, they were uncommon in the early 2000s. Beyond EHRs' critical role in medical practice and billing, they have become a very useful adjunct for a large variety of research applications. Furthermore, they arguably have become the primary foundation for precision medicine research and implementation.

The work supported by NLM fostered much of the evolution, proliferation, and utility for research of modern-day EHR systems [14]. Here, the authors focus on NLM's influence on the evolution of precision medicine. Dr. Lindberg pioneered the use of computers in medicine while at the University of Missouri in Columbia in the 1960s, building a system to help providers select antibiotic therapies [15-16]. Using the definition of precision medicine above, many have argued that infectious disease represents one of the first instances of precision medicine by precisely naming a patient's disease etiology and pairing it with a precise treatment. In this sense, Dr. Lindberg could be seen as one of the earliest purveyors for precision medicine (and later a tireless evangelist for it).

Under Dr. Lindberg's leadership, the NLM embarked on a long history of intramural and extramural support of EHR-related work that proved transformative to precision medicine. NLM participated in the trans-NIH Biomedical Information Science and Technology Initiative (BISTI), which funded the National Centers for Biomedical Computing. Particularly notable among the BISTI awards was the Informatics for Integrating Biology & the Bedside (i2b2) site, which leveraged EHR data for secondary discovery [17].

The i2b2 project developed a scalable, modular system with a flexible database structure that simplified ingestion and representation of EHR data. The i2b2 point and click graphical user interface provided its users with the ability to query EHR data without having to know specific data structures, programming, or database query languages. Before i2b2, EHR data mining was constrained to sites where a small subset of data engineers had internal access to the EHR; many of these engineers had competing operational responsibilities. With the introduction of i2b2, anyone at an i2b2 site with web access and appropriate credentials could carry out the data mining tasks. Thus, the i2b2 platform accomplished for EHR mining what NLM/NCBI's PubMed did for literature retrieval - bringing powerful information access as close to the end user as possible. The modular framework (cells) and API of i2b2 also made development of tools that worked across different institutions and installations of i2b2 possible [18]. In addition, the i2b2 project sponsored natural language processing (NLP) healthcare-related programming challenges. The competitions engaged investigators from across the world who competed to solve clinical EHR problems, including de-identification, medication extraction, and named entity recognition. Many of these new methods were publicly available and applicable to precision medicine.

The NLM's Unified Medical Language System (UMLS) provided an interlingua cross-referencing among existing standard vocabularies and provided a resource for synonymy and conceptual relationships [3]. Intramurally-developed NLM tools such as MetaMap and SemRep leveraged the UMLS and provided powerful methods for investigators worldwide to access the literature and analyze clinical narrative texts. These systems, designed first for application to biomedical literature, quickly proved to have utility to support research using data from clinical information systems. Many investigators built clinical NLP systems using the UMLS within their institutions, such as KnowledgeMap and Apache cTAKES [19-20]. Recently, such systems were leveraged to provide real-time NLP-based support for serious rare adverse drug events (Steven Johnson Syndrome and torsade de pointes) with known genetic influences [21].

From Dr. Lindberg's earliest days working with EHRs and decision support systems, he recognized the need for investment in the basic science of the EHR, which laid the groundwork to support precision medicine and EHR-based genomic discovery. Research program grants were regularly awarded to EHR "basic science topics" such as: clinical

decision support; EHR design; data representation; artificial intelligence/machine learning; interoperability; de-identification; genomic integration; and countless other topics.

A true mark of the success of NLM's pioneering work related to sponsoring EHR-related research is the expansion of EHR-focused grants sources from NLM to other NIH institutes and centers [22]. A query of NIH RePORTER for awards including the keywords "Electronic Health Record" or "Electronic Medical Record" reveals that all NIH institutes and centers have supported EHR work following NLM's initial funding. NLM-funded EHR projects have identified candidates for: clinical trials; sought to risk/error detection and safety/quality assurance; processed healthcare related imaging; explored genome-phenome correlations; developed natural language processing tools; supported de-identification; and sought to improve EHR interoperability. On a personal note, one of the authors (Denny) received his first R01 from NLM, supporting the development of phenome-wide association studies (PheWAS) and its derivatives.

The paradox of precision medicine is that it requires huge data sets to make accurate inferences about an individual. The huge cohorts required to support interrogation and discovery of genotype-phenotype relationships at an omic scale would not be possible without the use of population scale health record data. EHR-based DNA biobanks began with resources such as Crimson at Harvard launched in the early 2000s and BioVU at Vanderbilt launched in 2007 [23-24]. These biobanks were built on principles, algorithms, and technology funded in part by the NLM. These biobanks also laid the foundation for National Human Genome Research Institute (NHGRI)'s Electronic Medical Records and Genomics (eMERGE) network, which started in 2007 [25]. Today, many national and international biobanks leverage EHR data as a key source of phenotype data, including the UK Biobank, Million Veteran Program, FinnGen, China Kadoorie Biobank, and the *All of Us* Research Program. The International HundredK+ Cohorts Consortium (IHCC), which includes all of these biobanks and many more international resources, now boasts more than 50 million individuals, many of which have genomic data linked to EHRs [26].

One cohort that perhaps epitomizes the evolution of EHRs in the United States to support precision medicine discovery is NIH's "All of Us" Research Program, which was launched nationally in 2018 and has as its goal the recruitment of one million diverse participants from across the United States [27]. Research participants share information surveys, EHR information, and collect samples for whole genome sequencing. The EHR information is harmonized across more than 50 sites, 16 different vendor systems, and with participant-completed health survey data into a common data model. In addition, participants can share EHR information directly from their healthcare providers via Fast Health Interoperability Resource (FHIR) APIs. Researchers access the data via a web portal.

In addition to being a vehicle to enable rapid and robust discovery to support precision medicine, EHRs are necessary to implement precision medicine. Early on, Dr. Lindberg recognized that computer systems could improve the care decisions made by providers. The same principle of using data to direct antibiotic therapy is even more relevant when considering the volume of genetic variants and their often non-obvious nomenclature (e.g., genetic variants are named for location or assigned numbers rather than named based on their medical relevant effect). Pharmacogenomic variation is a key example of the need to support physician prescribing through advanced clinical decision support (CDS). Consider clopidogrel, an antiplatelet therapy, is a prodrug which is metabolized by CYP2C19 into its active metabolite 2-oxoclopidogrel. Variants

CYP2C19*2 or *3 lead to decreased levels of the primary functional metabolite (and thus decreased efficacy to prevent thrombosis), whereas CYP2C19*17 leads to increased efficacy [28]. There are an increasingly large number of known genetic variants affecting therapy or diagnosis that can be supported through advanced EHR-based decision support systems.

5. Some Examples of Precision Medicine Enabled by NLM's work

In a recent case report, a newborn baby was found to have an undiagnosed encephalopathy in the emergency department [29]. The baby had a sibling with a similar presentation who died at age 11 months without a clear diagnosis a decade earlier. Care providers ordered rapid genomic sequencing for the newborn and compared the result with the reference genome and aforementioned variant genome databases. The providers identified a pathogenetic mutation and made a diagnosis of thiamine metabolism dysfunction syndrome 2 (THMD2, OMIM: #607483) - all within a day. After the diagnosis, the therapy was simple: high dose dietary supplement of thiamine and biotin. The newborn's symptoms resolved. The leading author of the case report said during an interview, "Only about a third of sick babies with a suspected genetic disease who have their genomes sequenced get a firm diagnosis… And only 10% of those babies have treatment options once the condition is identified" [30].

Research demonstrates that genetic diseases may more commonly underlie common disease than previously projected. Actionable hereditary syndromes, causing diseases such as cancer and arrhythmias that could be averted if known, affect more than two percent of the population [31]. Whole exome sequencing has identified genetic causes for up to 10 percent of patients with chronic kidney disease [32]. Perhaps the most common example in practice today is precision oncology: identifying driving mutations and cytogenetic aberration has become the standard of care. An arsenal of molecularly-targeted agents are already FDA-approved, such as many receptor kinase inhibitors, PARP-inhibitors for BRCA-deficient cancers, immune-checkpoint inhibitors, and many monoclonal antibodies.

For example, anaplastic thyroid cancer used to be one of the most aggressive and devastating cancers; it often resulted in death within weeks of diagnosis. Now, novel anti-BRAF and MEK inhibitor combination therapy has achieved progression-free status in more than 50 percent of patients after a median follow-up of 47 weeks [33]. One of the newest anti-cancer approaches being used is chimeric antigen receptor T cells (CAR-T) therapy which modified host or donor T cells precisely to be reactive to an individual's specific cancer [34].

The intersection of vast data resources like EHRs linked to genetic data and computable NLM information resources like OMIM make available the possibility of computational approaches to uncover potential unrecognized genetic diseases. Patient presentations documented in the electronic health records for other seemingly unrelated clinical encounters might be a great resource to identify these patients. For example, Bastarache and colleagues developed the phenotype risk score (PheRS) approach, which mapped International Classification of Diseases (ICD) billing codes to phenotype terms (in Human Phenotype Ontology [HPO]) in the OMIM Clinical Synopsis [35]. Terms were weighted according to their frequency in the EHR. PheRS successfully predicted variant pathogenicity and identified patients who carry pathogenic mutations and who

had never been diagnosed before. PheRS is now being used regularly to help interpret variants of uncertain significance in the Undiagnosed Disease Network.

6. NLM's Work Laid a Necessary Groundwork for a Rapid Response to COVID-19

It is almost imperative that any story written in 2021 reflect on Coronavirus disease 2019 (COVID-19) as a litmus test for the success of health care institutional strategic plans. The COVID-19 pandemic has been a stark reminder for the importance of basic medical research, rapid data sharing, and interoperability [36-37]. This episode provides a measure of relevance for many of the principles initiated by Dr. Lindberg at the NLM.

After recognition as a novel syndrome in December of 2019, the virus was first sequenced and identified as SARS-CoV-2 on January 9, 2020. The first vaccine candidate was developed four days later and in Phase 1 clinical trials a mere 63 days following. Vaccines were in use in the United States 11 months after the sequence was discovered. These truly remarkable accomplishments stood on the shoulders of foundational biological discovery, rapid innovation, and devoted, collaborative work across the world where information was freely shared. The NCBI housed and made available SARS-CoV-2 sequence data in real-time. Many COVID-19-related tools and literature searches, including preprints, were facilitated through custom adaptations of NCBI tools.

The rapid implementation of COVID-testing nationwide exemplifies the critical role of NLM in modern laboratory medicine. In March 2020, the explosive pandemic caught the world's major healthcare systems unprepared. In the early days, a key frustration was the limited availability of diagnostic assays, not just in the US, but also in Europe and China. There were no industry standards or guidelines to develop and validate PCR assays for SARS-CoV-2. Many clinical and research laboratories had to develop the tests from scratch. The RNA genome of the SARS-CoV-2 virus had been sequenced early when the virus was first discovered in China and was available to the public via GenBank, so designing primers to amplify the virus sequencing for detection was relatively easy. The more difficult part of the design was to make the assay specific to SARS-CoV-2 because there are many non-COVID-19 circulating coronaviruses.

Thanks to the large deposit of previously sequenced different coronavirus genomes in the GenBank, laboratories were able to find sequence targets that were unique to SARS-CoV-2. Then, the next question became how a laboratory could validate its assay, because the real confirmed positive cases/specimens were rare and not available for most of the laboratories. A workaround at that time for many laboratories was to artificially synthesize part of the viral sequences, built upon the GenBank library, and spike them to non-COVID patient specimens to obtain parameters (such as sensitivity, specificity, and limits of detection) for Emergency Use Authorization by the FDA [38].

The freely available genomic sequence data hosted by NCBI contributed to the massive expansion of testing capacity within the United States. Multiple public-private partnerships were made possible to deliver state-of-the-art fast turnaround testing platforms for various scales, such as Abbott Laboratories, Roche Diagnostics, BioFire Diagnostics, and many other FDA-authorized diagnostic platforms, as well as reference laboratories, such as Quest Diagnostics, LabCorp, Mayo Laboratories, and many others. Of note, many of these COVID-testing platforms were built upon existing widely used genomic platforms for precision cancer diagnosis (such as Roche) and microbiology

(such as Abbott and BioFire). Indeed, precision genomic diagnosis based on publicly available sequence information greatly aided laboratory medicine in the last decade even before the pandemic.

Novel consortia, such as the National COVID Cohort Collaborative (N3C) and Consortium for Clinical Characterization of COVID-19 by EHR (4CE), were assembled in unprecedented time to pull together huge clinical data sets that enabled rapid investigations of COVID-19 risk factors, treatments, and outcomes. Data were mapped to common data models and made accessible to researchers through existing cloud-based technologies. A number of these efforts could draw their origins from people and work supported by NLM, such as i2b2 and SHRINE; basic research in common data models, controlled terminologies and the UMLS, and data harmonization; de-identification work to allow for safer clinical data sharing; and algorithms for analyzing EHR work. Each of these enabling NLM components began under Dr. Lindberg's leadership at NLM.

7. Conclusion

Broadly inclusive information, data, and discovery are the key to rational therapy, the goal of precision medicine. Dr. Lindberg's 31 years at NLM were a time of a dramatic information transformation, and with his leadership, the NLM led a remarkable information revolution related to biomedical data. Today, the NLM hosts biomedical knowledge repositories that are accessed millions of times daily and have become an irreplaceable catalog for literature and data. True to NLM's original mission, these data and information are curated, cross-indexed, and mapped with common vocabularies. The NLM's bioinformatics resources are the backbone of current molecular medicine, and the electronification of healthcare through EHRs helped create the big data essential to begin to untangle genome by phenome analyses (on the order of 10^{13} within current large biobanks). Thanks in part to Dr. Lindberg's leadership, the NLM has entered an emerging era equipped to continue to facilitate the transition to data-driven, precision medicine.

Acknowledgments

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The U.S. National Library of Medicine and Standards for Electronic Health Records: One Thing Led to Another

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Abstract. When Donald A.B. Lindberg M.D. became Director in 1984, the U.S. National Library of Medicine (NLM) was a leader in the development and use of information standards for published literature but had no involvement with standards for clinical data. When Dr. Lindberg retired in 2015, NLM was the Central Coordinating Body for Clinical Terminology Standards within the U.S. Department of Health and Human Services, a major funder of ongoing maintenance and free dissemination of clinical terminology standards required for use in U.S. electronic health records (EHRs), and the provider of many services and tools to support the use of terminology standards in health care, public health, and research. This chapter describes key factors in the transformation of NLM into a significant player in the establishment of U.S. terminology standards for electronic health records.

Keywords. Donald A.B. Lindberg M.D., U.S. National Library of Medicine, Logical Observation Identifiers Names Codes, RxNorm, Systematized Nomenclature of Medicine, Electronic Health Records, Health Information Exchange

1. Introduction

When Donald A.B. Lindberg M.D. became Director in 1984, the U.S. National Library of Medicine (NLM) was a leader in the development and use of information standards for published literature [1]. He viewed NLM's work on publication standards as highly appropriate for a national library and encouraged it [e.g., 2-4]. Although Dr. Lindberg saw electronic health records as essential and inevitable, he had no plan to extend NLM's standards efforts to clinical data. In 1985, when offered a possible opportunity to take over responsibility for maintaining the Systematized Nomenclature of Medicine (SNOMED) from the College of American Pathologists (CAP), he declined to pursue it: "NLM doesn't have patients." In his view, the Library lacked the mission, the expertise, and the source data to develop and maintain terminology for clinical systems.

Yet, by the time Lindberg retired in 2015, NLM had been the Central Coordinating Body for Clinical Terminology Standards within the Department of Health and Human Services (HHS) for 11 years [5]. NLM funded the maintenance and free dissemination of two international standards, Logical Observations Identifiers Names Codes (LOINC)

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and SNOMED. NLM also produced RxNorm, the U.S. standard for clinical drugs; the distributor of DailyMed, a database of standard structured product labels for drugs submitted to FDA; and became the developer of the Value Set Authority Center, terminology subsets, and other tools for facilitating the use of standards in U.S. electronic health records and research data [e.g.,6-9]. NLM was instrumental in the development of the Uniform Code of Units of Measure (UCUM) computable standard, an electronic standard for newborn screening reports, and a database of common data elements (CDEs) for biomedical research [10-12].

This chapter describes how NLM became one of many significant players in U.S. efforts to demonstrate the value and increase the use of electronic health records (EHRs) and supporting standards and then to mandate their use [Endnote 1]. Many factors contributed to this outcome including: the Unified Medical Language System (UMLS); Lindberg's pre-NLM informatics and health services research contacts; helpful actions by the Institute of Medicine (IOM) (now National Academy of Medicine); the U.S. Congress, HHS, and other federal agencies. Other contributions included: Lindberg's appointment as the first Director of the National Coordinating Office for High Performance Computing and Communications (HPCC); and his decisions to use NLM's authorization to "engage in such other activities as the Secretary [of HHS] determines appropriate and as the Library's resources permit" [13-16].

2. The UMLS Project Gives NLM Special Expertise

When Lindberg became NLM Director in 1984, he expected an enormous expansion in the universe of electronic information and data applicable to health care and biomedical research. He initiated the UMLS project in 1986 to facilitate development of advanced information systems that could retrieve and integrate related information from disparate electronic sources, e.g., patient records, literature databases, databanks, irrespective of differences in the terminologies used within them [17].

Following a 1986-1988 exploratory period, NLM and Lexical Technology, Inc. (LTI), a UMLS research contractor, built the first version of the UMLS Metathesaurus, a novel knowledge source intended for use by system developers, in 1989-1990 [13]. Building the Metathesaurus involved: analyzing then underspecified semantics of multiple biomedical vocabulary sources; converting relatively primitive machine-readable versions to a common fully specified relational format; using advanced lexical matching methods and human experts to group synonymous terms and codes into concepts; and assigning each concept at least one Semantic Type, e.g., Disease or Syndrome. Body Part This process gave NLM specialized knowledge of the content, structure, and informatics properties of multiple terminologies and code sets. As additional vocabulary sources were incorporated into editions of the Metathesaurus, NLM's understanding of their strengths and weaknesses and their degree of overlap deepened.

Lindberg's UMLS Project Director, Betsy Humphreys M.L.S., fielded many questions about the Metathesaurus' purpose and characteristics. In the process, Humphreys learned why a well-structured, freely available clinical terminology standard was needed for EHRs and why the standardization of EHRs would make the UMLS goals easier to achieve.

3. The Institute of Medicine and the U.S. Congress Increase NLM's Focus on Health Services Research

In 1986, a Council on Health Care Technology was established at the Institute of Medicine (IOM), U.S. National Academy of Sciences in response to federal legislation [Endnote 1]. Among other responsibilities, the Council was to develop a clearinghouse for information on health care technologies and technology assessments, broadly defined. Morris Collen M.D., a member of the Council's Information Panel, encouraged the group to "talk to Don Lindberg" for advice and to avoid duplicating NLM services. Lindberg was known to the health services research (HSR) and technology assessment community as the previous principal investigator of the National Special Emphasis Center on Health Care Technology, an HSR center funded by the National Center for Health Services Research (NCHSR) in the 1970s [14].

Lindberg joined the Council's Information Panel. Humphreys directed a comparison of the contents of the Council's draft - Medical Technology Assessment Directory: A Pilot Reference to Organizations, Assessments, and Information Resources - with the coverage of NLM services. Although deficiencies in NLM coverage were noted, the analysis showed expansion of existing NLM resources could cost-effectively satisfy many of the information needs related to technology assessment [18]. The 1989 legislation establishing the Agency for Health Care Policy and Research (AHCPR) (and eliminating the Council and NCHSR) assigned tasks to NLM to be supported by a funds transfer from AHCPR. As NLM's engagement with the HSR community increased, Humphreys realized both the UMLS and standardized EHRs could lead to better data for HSR.

As desired by Lindberg and AHCPR - and strongly advocated by the Association for Health Services Research (AHSR) - Congress gave NLM direct authorization and appropriated $8 million to establish the National Information Center for Health Services Research and Health Care Technology (NICHSR) in 1993. Lindberg appointed Humphreys NLM Assistant Director for Health Services Research Information (concurrent with her position in Library Operations). Lindberg, Humphreys, and AHSR believed that a major goal for NLM's NICHSR was "to contribute to the information infrastructure needed to foster patient record systems that can produce useful health services research data as a by-product of current health care" [19]. This provided an explicit rationale and budgetary support for increased NLM involvement in health data standards work, including relevant additions to the UMLS.

4. NLM Develops a Position on Achieving U.S. Clinical Terminology Standards

In the early 1990s, the IOM, the American Hospital Association (AHA), the health insurance industry, HHS, and standards development organizations all took steps to sharpen the U.S. focus on electronic data interchange, EHRs, and their supporting standards. As the 1992 U.S. Presidential election approached, the Clinton campaign, with its focus on health care reform, encouraged the U.S. informatics community to develop policy positions.

Due to Lindberg's expertise and the UMLS project, NLM was invited to participate in many standards-related activities. Lindberg was a federal liaison to the IOM Committee on Improving the Patient Record in Response to Increasing Functional Requirements and Technological Advances, chaired by Don Detmer M.D. Many

informatics pioneers contributed to its landmark 1991 report - The Computer-Based Patient Record: An Essential Technology for Health Care [20]. Humphreys served on the study's Technical Subcommittee and soon as the NLM representative to many other committees, including the Computer-Based Patient Record Institute (CPRI) and the American National Standards Institute (ANSI) Healthcare Informatics Standards Planning Panel, formed in 1991 to coordinate U.S. health data standards activities [21].

Given her representation of NLM, and sometimes the National Institutes of Health (NIH) as a whole, in discussions about EHRs and standards, Humphreys consulted with Lindberg to develop an NLM position on what was needed to achieve U.S. clinical terminology standards. By early 1992 they agreed NLM should promote the following U.S. federal health data standards agenda:

(1) establish a U.S. federal mechanism for selecting standards applicable to all U.S. health care and public health entities
(2) select the best available set of vocabularies as target U.S. standards
(3) provide ongoing federal support for maintenance, enhancement, and free dissemination of the selected vocabularies
(4) support testing and feedback from real clinical settings *before* any federal mandate for use.

Lindberg and Humphreys had no firm expectation about the specific role NLM would play in making these ideas a reality.

The ideas were not original to NLM, but the emphasis on the necessity for a federal selection mechanism and federal support for maintenance and free dissemination of terminologies *was*. Voluntary adoption of terminology standards was unlikely given the diversity of interests in U.S. health care. Congressional action was needed because no federal agency had the authority to impose common standards across U.S. health care and public health. However, such action looked possible in the early 1990s, given the Clinton campaign's health care focus. NLM saw the necessity to select a limited set of existing terminologies as target standards to focus development and testing and make them fit for purpose sooner. NLM also was convinced federal support for maintenance and free dissemination was necessary to achieve widespread adoption of clinical terminology standards. Uncertainty about future price increases and intellectual property restrictions would discourage use. Of course, it would be important to promote use and improve the target terminology standards before mandating them.

Once NLM had an agreed position on any topic, Lindberg was comfortable giving a designated senior staff member, in this case Humphreys, leeway in deciding how, when, and where to pursue it. Lindberg's primary stipulation was that, in this arena, NLM should always proceed in cooperation with other federal agencies.

5. The HPCC Initiative Provides New Opportunities for Promoting EHRs and Standards

In 1992, Lindberg became the first Director of the National Coordination Office for HPCC, which was part of the President's Office of Science and Technology Policy, (serving concurrently as NLM Director) [15]. This appointment led to substantial funding to support health applications of HPCC technologies; acceleration of NLM use of high-speed communications and web technology, including in UMLS construction and distribution; and a request from HHS to promote public health involvement in the

emerging National Information Infrastructure (NII) and health data standardization. These created opportunities to advance EHRs and NLM's standards agenda.

In 1993, NLM solicited proposals for projects that could demonstrate the integration of HPCC technologies into health care applications, including "test bed networks for linking hospitals, clinics, doctor's offices, medical schools, medical libraries, and universities to enable health care providers and researchers to share medical data and imagery." Twelve contracts were awarded by April 1994 [22]. In September 1994, NLM, in partnership with AHCPR, awarded five of the eventual eight cooperative agreement grants for research on aspects of EHRs. In announcing them, Lindberg said, "Computer-based patient records are critical to improving the quality and reducing the cost of health care. Much work has been done on electronic patient records, but no fully satisfactory, complete system exists as yet." The new awards "will help foster development of working systems suitable for both inpatient and outpatient care, and capable of providing data useful in health services research, including technology assessment and outcomes research."[23]. Several of the awards were focused on terminology for patient data.

- In 1994, NLM added the SPECIALIST lexicon and lexical programs to the UMLS release. In combination with the UMLS Metathesaurus and Semantic Network,
- the two services provided powerful tools for matching local terminology to controlled vocabularies and code sets (and revolutionary for biomedical natural language processing) [24].
- In 1995, NLM provided UMLS resources via an Internet server with a Web interface, a command line interface for batch processing, and an application programming interface (API) [25]. This provided a platform for NLM and AHCPR to engage the cooperative agreement partners and others to conduct a large-scale test to determine how well existing biomedical vocabularies covered terminology needed for EHRs [26]. In December 1994, Lindberg and Clifton Gaus Sc.D., AHCPR Administrator, opened a two-day meeting at NLM to identify the set of vocabularies to be included in the test and "to advance the broader agenda of establishing a reasonable starting point for the development and maintenance of a "standard" vocabulary for use in computer-based patient records" in the U.S. [27-28]. One presenter had never seen "so many vocabulary nerds in one room." Lindberg was definitely an outlier.

Also in 1994, after the Clinton health reform failed, Philip Lee M.D., Assistant Secretary for Health (ASH), and Roz Lasker M.D., Deputy Assistant Secretary for Health (Policy), established a Public Health Data Policy Coordinating Committee to provide a public health voice on data issues to balance the perspective of the Health Care Financing Administration (HCFA). Humphreys attended a preliminary meeting with Lasker and saw an opportunity to advance NLM's position on the importance of clinical data standards to research and public health and the need for federal support for them. Humphreys was appointed the NIH representative to the committee, setting a precedent for NLM's inclusion in all subsequent HHS health data standards committees. The committee's agenda included consideration of the federal role in supporting data standards, the need for greater public health participation in standards development, and the poor information technology infrastructure in public health departments.

Lee and Lasker met with Lindberg to discuss how to promote collaboration between the medical informatics and public health communities, achieve more public health involvement in the NII, and advance public health participation in data standardization. Lee and Lindberg had been colleagues since the time when both directed NCHSR-funded

centers in the 1970s. Lindberg suggested an invited meeting as an initial step. On April 19, 1995 (the Oklahoma City bombing day), NLM, the Office of the ASH, the Centers for Disease Control and Prevention (CDC), and AHCPR convened an invited conference, "Making a Powerful Connection: The Health of the Public and the National Information Infrastructure" and a smaller strategy session on April 20. The 120 conference attendees included representatives of federal agencies, foundations, state and local public health departments, associations, NLM-funded informatics training programs, and the National Network of Libraries of Medicine (NNLM). The meeting and the resulting report and recommendations from the Public Health Data Policy Coordinating Committee had significant immediate and long-term effects, including on NLM informatics training and research programs and standards activities [29-31].

6. NLM HPCC Funding Triggers Development of a Health Information Exchange

NLM's 1993 request for proposals for HPCC applications "provided the spark," and in April 1994 NLM initially funded the development of the Indianapolis Network for Patient Care (INPC), later renamed the Indiana Network for Patient Care [32]. Clement McDonald M.D., then Director of the Regenstrief Institute, was the principal investigator (PI) on the proposal to integrate medical data from three inner city Indianapolis hospitals into the Regenstrief Medical Record System. The technical reviewers were impressed by the strong letters of support from the locally "competing" Wishard Memorial, Indiana University, and Methodist Hospitals. Lindberg was not surprised ("Clem has been there a long time. They trust him."). Lindberg preferred to fund novel applications in environments conducive to rapid production of working systems.

In the INPC, the data from each contributing organization was sent to the Regenstrief Institute using HL7 v2 messages and stored respectively in their own separate file systems. All the file systems had the same database structure and were tied to a single common term dictionary. A record linkage system connected patient registration records together as they were received from each site. The net result was that providers at each hospital could see a patient's data from all three hospitals in one uniform view as though from a single system, but only when a patient was currently under their care as verified by their hospital's registration system.

With additional NLM HPCC funding in 1996, the network expanded to five institutions and 12 hospitals all within Indianapolis. A connection to public health departments was established at NLM's request. The funding was approved by Lindberg as the best way to create a demonstration of electronic notifiable disease reporting. The INPC was a hit with care providers, especially emergency room (ER) providers [33]. Analysis of INPC data showed considerable overlap among the patients seen in different ERs in the same region [34].

The INPC was the first operational Health Information Exchange (HIE) and provided a model for many HIEs that followed. A web application called CareWeb, still in operation, gave providers a unified view of their patients' medical data generated at any hospital. It included almost every kind of structured test result, as well as narrative discharge summaries, operative reports, and other kinds of notes. In its later years, it presented radiology images and EKG tracings from some institutions. A second application called Docs4Docs delivered all diagnostic reports and provider dictation to the provider's office. The INPC was the first to deliver electronic notifiable disease test

results to a state public health department (Indiana's) - four times more of them, faster and with more complete detail than the manual system [35].

The modest Indianapolis HIE that began life in 1994 with NLM funding that Lindberg obtained from the HPCC program has continued to operate and grow. Today, the Indiana Health Information Exchange (IHIE) serves 20,000 care providers from Indiana and adjacent states and encompasses 12 billion structured observations and hundreds of millions of narrative reports and radiology images from more than 100 health care organizations - all in the service of better health care.[36]

7. Health Information Exchange Highlights the Need for a New Standard

The INPC provided an early visible demonstration of the value of health data standards and the need for one more of them. The Indiana investigators could not have created the INPC without the HL7 v2 message standard. Fortunately, in 1994 HL7 v2 had existed for more than seven years and had been adopted by many health care systems. At that time, HL7 did not require use of any specific code system to identify test results, and there was no viable candidate for practical adoption in the U.S. Each hospital invented its own idiosyncratic code system.

To build the initial INPC, Regenstrief had to hand map hospital specific codes to the Regenstrief local "standard" in the term dictionary. This was labor intensive and not easily scalable to the anticipated expansion of the INPC, let alone broader efforts to merge data for health care, research, and public health.

Foreseeing this problem prior to receiving HPCC funding in April 1994, Regenstrief organized an international committee of medical informatics and laboratory experts to develop standard names and codes for clinical observations, starting with laboratory test results. If all producers of test results used standard names and codes in their HL7 messages, the results could easily be merged into any EHR or HIE. As the committee began its work, McDonald submitted an application in response to the joint NLM-AHCPR request for cooperative agreement proposals for research on requirements for networked EHRs, including new, practical approaches to vocabulary issues. The AHCPR funded it in September 1994, thus providing additional support for early LOINC development.

Stanley Huff M.D., co-chair of the LOINC committee, gave the LOINC presentation at the NLM-AHCPR meeting in December 1994 that chose the vocabularies to be included in the planned large scale vocabulary test [27]. His presentation introduced most of the attendees to LOINC for the first time. The consensus reached was to include in the test all vocabularies already in the UMLS, plus the rest of SNOMED, the UK Read Codes, and LOINC. Version 1 of LOINC was released in April 1995 [37].

8. HIPAA Changes the Standards Playing Field

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) gave the Secretary of HHS responsibility to make regulations to establish standards for electronic transmission of administrative health transactions, code sets, and security, among others. Standards were to be adopted within 18 months, with compliance required two years later. Non-compliance carried penalties. The Secretary was required to take advice from National Committee on Vital and Health Statistics (NCVHS) in establishing HIPAA

standards. The law expanded the NCVHS and charged it to "study the issues related to the adoption of uniform data standards for patient medical record information and the electronic exchange of such information" and make recommendations by 2000 [38].

Finally, there was a federal mechanism for selecting administrative data standards applicable to all U.S. health care entities and the potential for extending it to clinical data standards. The selection of existing standards was specified as the preferred approach, and, in language Humphreys helped to draft, the Secretary was required to "establish efficient and low-cost procedures for distribution (including electronic distribution) of code sets" and their modifications [39]. Inclusion in the UMLS would soon be viewed as important to meeting this requirement.

NLM's first contribution to HIPAA's implementation was funding a short extension to a Lindberg-commissioned National Academies study on maintaining privacy and security in health care applications of the National Information Infrastructure. This enabled the committee to make its 1997 report, *For the Record: Protecting Electronic Health Data,* directly suitable as the basis for HIPAA security standards [40]. Lindberg had charged the study committee to visit hospitals and a public health department, a very unusual requirement for an Academies study at the time. Lindberg thought the computer scientists in the group should see health data systems before making recommendations for them.

HIPAA was a milestone on the road to health data standards, but it came with an enormous workload. When Humphreys was asked to co-chair the HHS Coding and Classification Implementation Team, Lindberg and she decided that helping with the administrative standards work would enable NLM to influence later recommendations on EHR standards. NLM supported the NCVHS Workgroup on Computer-Based Patient Records (McDonald was a member) as it developed the 2000 report on standards for EHR information. In 1999, CAP and the U.K. National Health Service announced plans to merge SNOMED and the Read Codes, thus simplifying U.S. clinical terminology selection.

Humphreys proposed creating an example of federal support for maintenance of a required terminology. Lindberg approved if other federal agencies participated. In 1999, NLM issued a contract to support the ongoing maintenance of LOINC, with financial contributions from the U.S. Department of Veterans Affairs (VA), the U.S. Department of Defense (DOD), and HCFA. The case for LOINC was relatively easy; it was freely available and slated for mandate in the HIPAA claims attachment transaction. As of 2021, NLM still supports LOINC maintenance and expansion, as do other agencies, although no HIPAA claims attachment standard yet exists. Lindberg's 1999 view of health data standards work appeared in NLM's Long Range Plan for 2000-2005. It included a program plan to "work with other Federal agencies and outside organizations to support the establishment, ongoing maintenance, testing, and use of health data standards to enhance the quality of care and improve the data available for research." [41].

Early in 2000, the U.S. National Cancer Institute (NCI), VA, and CDC approached Humphreys about NLM negotiating a U.S. government-wide license for use of SNOMED. A federal-only license did not address a national need to exchange and aggregate health data across federal, state, and private sector entities, but Humphreys consulted with Lindberg about trying for a U.S. nationwide license. The NIH budget was then doubling so the suggestion's timing was good. Lindberg was firm that NLM needed to launch new programs, e.g., consumer health, ClinicalTrials.gov, with the increase, not just do more of the same. Given HHS' backing, Lindberg was willing for NLM to try to negotiate a novel license arrangement and to consider it one of NLM's new programs, if

a reasonable deal were reached. In June 2000, NLM issued a sole-source procurement to CAP for a nationwide license for SNOMED, with experts from other agencies serving as technical advisors.

9. The George W. Bush Administration Embraces EHRs and Standards

The July 2000 NCVHS report on standards for EHR information recommended the HHS Secretary accept proposed criteria for selecting clinical data standards and forthcoming recommendations of clinical standards for adoption by government agencies. This was a HIPAA-like process, minus regulation, to establish target U.S. standards and promote testing before mandating use. The report recommended "government-wide licensure or comparable arrangements" to make terminologies available "at little or no cost" and action on drug terminology [42]. There was no HHS response in the waning days of the Clinton Administration.

When George W. Bush won the 2000 U.S. election, some worried about diminished interest in health data standards. As it happened, Tommy Thompson, the new HHS Secretary, expressed strong support for standards very early in his tenure, following a meeting with John Lumpkin M.D. and Don Detmer M.D., current and former NCVHS chairs. The staff in the Office of the HHS Assistant Secretary for Planning and Evaluation, VA, and DOD succeeded in focusing the U.S. Office of Management and Budget e-Gov health initiative on government-wide adoption of clinical data standards. The Consolidated Health Informatics (CHI) e-Gov project became the vehicle for reviewing NCVHS recommendations and recommending adoption of standards by HHS, VA, and DOD. NLM was a CHI participant.

The negotiations for the SNOMED license were considered a critical CHI activity. Among the first standards to go through this process and be adopted by HHS, VA, and DOD in 2003 were LOINC and HL7. By that time, LOINC had grown from 5,900 names and codes, primarily for laboratory test results, to more than 34,000, a fifth of which were clinical observations, document types, and survey instruments.

Meanwhile at NLM, Stuart Nelson M.D. was defining a standard form for the names of "clinical drugs" to enable accurate linking of drug terminology in the UMLS [43]. The work built on previous HL7 efforts to define a standard form useful in clinical decision support. Commercial drug information sources, e.g., First DataBank, had prompted and participated in the HL7 project. Nelson's approach to solving the UMLS Metathesaurus construction problem was also a feasible way to build a standard clinical drug vocabulary to address NCVHS concerns and enable effective exchange and aggregation of EHR data.

Nelson presented the RxNorm proposal for Lindberg's approval, describing the planned electronic transmission of source data (structured drug product labels (SPLs) to NLM by the Food and Drug Administration (FDA) and complementary VA work on clinical properties of drugs, e.g., physiologic effects. Lindberg was enthusiastic about the project and collaboration with FDA and VA. He asked one typical question: "Will RxNorm be useful if the VA work doesn't proceed?" The answer was "yes" and RxNorm was first released in the 2002 UMLS and separately in 2004 [44]. In November 2005, NLM released DailyMed, the official distribution mechanism for current SPLs submitted to FDA by companies [45].

By mid-2002, NLM and CAP had agreed on the terms for a U.S. nationwide SNOMED license but remained far apart on price. NLM sent a letter ending the negotiations, responding to a CAP communication about a lowest acceptable figure.

Former Congressman John Porter soon called Lindberg to ask for a meeting with CAP representatives and himself to discuss a way forward. Lindberg readily agreed ("I'm always willing to meet") and included Humphreys and Donald King M.D., NLM Deputy Director for Research and Education. The discussion led to a new round of talks, with a fixed end date of January 15, 2003 suggested by Porter. Helped by King's communication with CAP leaders, a deal was reached in December 2002 at a price in NLM's range. A one-time fee for a perpetual license was covered by contributions from DOD, VA, and many HHS agencies. The annual maintenance fees were paid by NLM [46]. Secretary Thompson assigned the contribution level to each HHS agency. NLM and CAP signed the contract on July 1, 2003, and the huge job of incorporating SNOMED into the UMLS began.

The Secretary announced the SNOMED license at an HHS consensus conference on Developing the National Health Information Infrastructure (NHII) in Washington DC on July 1, 2003 [47-48]. HHS and NLM received universal praise, influencing subsequent Administration actions in 2004. These included: the Executive Order setting a goal for EHRs for the majority of Americans by 2014 and establishing the National Coordinator for HIT; the designation of NLM as the HHS central coordinating body for clinical terminology standards; and the placement at NLM of a short-term Commission on Systematic Interoperability required by the Medicare Modernization Act of 2003 [5,49]. Both SNOMED and RxNorm went through the CHI process and were adopted by HHS, DOD, and VA in 2004 [50]. In 2005, the National Coordinator for HIT funded a new Health IT Standards Panel, with Humphreys on the Executive Board, and the HHS Secretary, now Michael Leavitt, another strong supporter of standards, established the American Health Information Community (AHIC), a federal advisory committee focused on a broader agenda, including adoption of EHRs.

The U.S. nationwide license for SNOMED inspired the business model and licensing terms for the International Health Terminology Standards Development Organization (now trading as SNOMED International). The U.K. led its formation in 2007 to acquire SNOMED from CAP, manage its maintenance, share costs proportionally among member countries, and encourage international adoption and use in vendor products. NLM represented the U.S. as one of nine founding members. There are 40 member countries today [51].

10. Use of EHRs and Supporting Standards Becomes Mandatory

Lindberg's 2005 view of EHRs was explained in the closing section of the 2006-2016 NLM long range plan: "As reflected in special Presidential and Departmental initiatives, the country badly needs and wants better electronic health records. …We expect the need for electronic record systems to become more acute in the future. NLM should continue to contribute significantly to the solution." EHRs, health data standards, and clinical research data were central to one of the plan's four broad goals: "Integrated biomedical, clinical, and public health systems that promote scientific discovery and speed the translation of research into practice." A specific recommendation called upon NLM to promote the development of next-generation EHRs to support care, research, and public health [52].

Lindberg's interest in EHRs and standards was evident in McDonald's 2006 appointment as Scientific Director and Director of the Lister Hill National Center for Biomedical Communications (LHC). McDonald took the position only after confirming

that his continuing service on the LOINC Committee would not cause a conflict of interest. Lindberg believed in Personal Health records (PHRs), as earlier demonstrated by his positive view of health smartcards when serving as U.S. National Coordinator of G-7 Healthcare applications (1996-2000). "A person should be able to put all of his/her data into their personal health record. It is their data so they should have it and be able to know exactly what was going on with their health and to pass it to whomever they wanted." [53]. Lindberg urged McDonald to develop an NLM PHR and was disappointed when efforts to locate a hospital partner to test his standards-based PHR application with patients failed. (The initially interested hospitals were merged or acquired.) However, Lindberg's original idea still lives. At present, more than 800 institutions (including hospital networks and specialty practices) can deliver a patient's health care data to their iPhone. The Apple Health PHR is then able to receive those data using HL7 FHIR, present them in a user-friendly fashion, or display their underlying standard structures and codes at the click of a button.

In 2007, as HHS inquiries to NIH about health IT standards increased, Elias Zerhouni M.D., Director of NIH (2002-2008), asked Lindberg to chair a new Trans-NIH Biomedical Informatics Coordinating Committee (BMIC). Lindberg saw the assignment as improving communication about current projects related to clinical and bioinformatics at NIH and surfacing matters warranting consideration by NIH policymakers. The meetings were interesting and popular. The presentations and discussions led BMIC to establish the NIH Common Data Element (CDE) repository and create guidance for research data sharing plans [54]. In addition to updating BMIC members on the rapidly changing federal health IT picture, NLM staff used BMIC to promote use of health IT standards in clinical research, another longstanding NLM priority.

Overall, there is no doubt Lindberg would be pleased by recent progress in this area, e.g., the 2019 NIH guidance on use of HL7 Fast Healthcare Interoperability Resources (FHIR) and in 2020, on use of the coding/systems specified the U.S. Core Data for Interoperability (USCDI), including LOINC, RxNorm, and SNOMED [55-56]

McDonald arrived just in time to add his expertise to NLM's National Center for Biotechnology Information (NCBI) to implement the AHIC Personalized Care Workgroup's recommendations regarding standards for transmitting results of genetic tests and newborn screening in 2007. Ensuring that genetic test data could be incorporated in EHRs was a high priority for Secretary Leavitt. The NLM work involved an expansion of LOINC, input to a draft HL7 implementation guide, and development of RefSeqGene to include reference sequences for recording and interpreting clinically significant genetic variations [57].

At Lindberg's request, the NLM Board of Regents established a work group in September 2008 to assess the usefulness and budget of NLM's health data standards activities and to identify opportunities for NLM to advance standards development and deployment further. A significant opportunity arrived in February 2009 with passage of the Health Information Technology for Economic and Clinical Health (HITECH) Act, as part of the American Recovery and Reinvestment Act (ARRA). The latter established the Office of the National Coordinator for Health IT in law, created two new federal advisory committees on health IT policy and standards, and provided monetary incentives for the "meaningful use" of EHRs, which required use of designated clinical data standards. In May 2009, the work group recommended to the Board of Regents that NLM immediately create tools and services to help vendors and users incorporate terminology standards into EHRs and to align terminology value sets with data elements [58].

Once again, a National Academies study commissioned by Lindberg appeared at an opportune moment. Computational Technology for Effective Health Care was published in 2009 in time to influence ideas about "meaningful use" and solicitations for research and development projects supported by time-limited ARRA research funds, including those issued by NLM and the U.S. Office of the National Coordinator [59].

Although many thought they had been working hard on federal health IT priorities, the pace became frenetic in 2009. Standards already adopted for U.S. government-wide use under the CHI process were obvious candidates for selection as national HITECH "meaningful use" standards but required hearings and rulemaking to attain that status. At the same time, regulations were being developed for the incentive program and other HITECH provisions. Questions inevitably arose about whether LOINC, RxNorm, or SNOMED were suitable for a particular "meaningful use" purpose and whether there were sufficient tools and services to make implementation feasible. NLM's priority was to do whatever possible to ensure an affirmative answer to all the questions.

11. Concluding thoughts

By 2011, the U.S. had established national clinical data standards. Among them were LOINC, RxNorm, and SNOMED - all regularly updated and freely available. In broad strokes, what NLM outlined as its position on clinical terminology standards in 1992 had occurred. The desired result arrived two decades later with little doubt about NLM's primary role. Lindberg's vision for the UMLS, his willingness to take unprecedented steps carefully and with allies, and his long tenure at NLM were essential to this outcome.

Endnotes

[1] This chapter covers a piece of the much larger history of clinical data standards development and adoption in the U.S. It mentions by name only a few of the literally hundreds of people and the dozens of organizations that contributed to the events described. Some (but not all) additional contributors are among the authors of sources cited in the references.

[2] There had been earlier U.S. legislative attempts to establish a robust system of health technology assessment, amid concerns about rising Medicare costs and widespread adoption of new technologies without adequate evidence of their safety and efficacy. See: Blumenthal D. Federal Policy toward health care technology: the case of the National Center. Milbank Mem Fund Q Health Soc. 1983 Fall;61(4):584-613. DOI.org/10.2307/3349874.

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Something New and Different: The Unified Medical Language System

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Abstract. Donald A.B. Lindberg M.D. arrived at the U.S. National Library of Medicine in 1984 and quickly launched the Unified Medical Language System (UMLS) research and development project to help computer understand biomedical meaning and to enable retrieval and integration of information from disparate electronic sources, e.g., patient records, biomedical literature, knowledge bases. This chapter focuses on how Lindberg's thinking, preferred ways of working, and decision-making guided UMLS goals and development and on what made the UMLS markedly "new and different" and ahead of its time.

Keywords. Unified Medical Language System, Donald A.B. Lindberg M.D., U.S. National Library of Medicine

1. Introduction

When Donald A.B. Lindberg M.D. became the Director of the U.S. National Library of Medicine (NLM) in 1984, he strongly believed in the promise of computers to help people provide better patient care [1]. Nevertheless, he had experienced firsthand the difficulties of developing systems that could deliver on that promise. He arrived at NLM with the intention of launching a new informatics research and development effort aimed at reducing those difficulties. His visionary goal was to help computers "understand" biomedical meaning, in essence a "Grand Challenge" that predated use of the term in informatics. Lindberg wanted to enable the retrieval and integration of information from disparate electronic sources, e.g., patient records, biomedical literature, knowledge bases. His plan was in preliminary form, but it had a name: the Unified Medical Language System (UMLS); a specific problem to address: "… the most fundamental barrier to the application of computers in medicine; namely, the lack of a standard language in medicine;" and intended users: developers of computer applications and informatics researchers [2]. This was a novel target user group for him, for NLM, and the field of medical informatics.

Lindberg conceived of the UMLS project in the months between his selection as NLM's next director and his assumption of the position in late August 1984. He foresaw the inevitable exponential growth in the size, diversity, and importance of information sources in digital form. These would be critical in improving health care and biomedical research. He pondered what NLM might do to foster advanced new computer systems

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that could retrieve and integrate such disparate sources He was familiar with the difficulties caused by varying vocabularies and codes in different types of medical information. Then unusual in the medical informatics field, Lindberg had experience with diverse sources of data and had built disparate information systems. He had worked with digital lab results and electronic texts; used large, mainframe computers in production systems; and dealt with computational complexities, e.g., attempts to implement expert reasoning. He had served as an advisor to the NLM-funded project that produced the Association of American Medical Colleges (AAMC) report on Integrated Academic Information Management Systems (IAIMS) [3]. He understood that the language problem would become more acute as institutions attempted to integrate networked sources of clinical, administrative, and published research knowledge and then share the results of their efforts for re-use elsewhere.

In preparation for his move to NLM, Lindberg expanded his informal consultations with other medical informatics pioneers to obtain advice on what major new step NLM could take to advance computer applications in medicine. His discussions with Marsden Scott Blois M.D., Ph.D. were particularly influential. Blois published his foundational theory on the requirement for vertical reasoning in medical diagnosis, across multiple levels of information, from the patient as a whole - down to atoms or ions, each with its own vocabulary, in book form in 1984 [4]. Lindberg and Blois had separately used a machine-readable version of the American Medical Association's (AMA) *Current medical information & terminology (CMIT): for the naming and description of diseases and conditions in practice and in areas related to medicine* in pioneering systems that suggested possible diagnoses based on patient presentations [5-8]. Although unarticulated at the time, these activities formed a partial model for the UMLS: digital medical knowledge was provided for use by system developers. Both Lindberg and Blois attempted unsuccessfully to convince the AMA to continue producing updated editions of CMIT, an early effort to name and define all diseases using structured definitions.

By the time he arrived at NLM in August 1984, Lindberg had identified the UMLS as a long-term project that would play to NLM's strengths as a Federal Agency with a track record of technical innovation and development and use of standards. For example, NLM had already had success in building and maintaining the Medical Subjects Headings (MeSH) and large-scale medical information systems used worldwide. Experience had taught him that grant-funded academic institutions and professional associations were not ideally positioned to maintain large terminology resources over time. He intended to enlist both, however, in helping to define, develop, test, and refine what he anticipated as UMLS components. Any resources produced by the UMLS project would be freely available for iterative testing and experimental use by system developers and informatics researchers in the U.S. and other countries. This was another first for NLM, a commitment to "Open Science", again predating that term. It was viewed with concern by some producers of medical terminologies.

Much has been written about the UMLS project and the heavily used resources resulting from it [e.g., 9-13]. This chapter focuses on how Lindberg's thinking, preferred ways of working, and decision-making guided UMLS goals and development and on what made the UMLS markedly "new and different" and ahead of its time.

2. Establishing the UMLS Project

Following his preferred pattern for developing new projects, Lindberg circulated a brief statement about his "fuzzy" UMLS idea soon after his arrival at NLM. He began immediately to solicit input from his senior staff, Board of Regents members, and others encountered at the Library. As he often said, "No one has a lock on good ideas. They come from everywhere." By January 1985, he had established a multidisciplinary NLM UMLS Team. Two months later he asked Congress for additional FY1986 funding for the UMLS project, the first such request during his NLM tenure.

While awaiting the verdict on additional funding, Lindberg consolidated and expanded the NLM UMLS team, which he chaired. Harold M. Schoolman M.D. served as his chief lieutenant during this formative stage. They designated Betsy L. Humphreys M.L.S., as Executive Secretary of the team, which also included Lawrence C. Kingsland III Ph.D. and Peri L. Schuyler M.L.S. Collectively, the initial team had expertise in medicine, chemistry, terminology development, computer science, artificial intelligence, library and information science, standards, database development, production systems, and project and contract management. Lindberg regarded linguistics as an essential missing piece. When the first linguist tried was not a good fit, Lindberg persevered, and Alexa T. McCray Ph.D. joined the team in January 1986. Daniel R. Masys M.D. became a member of the UMLS team when appointed Director of NLM's Lister Hill National Center for Biomedical Communications in June 1986. William T. Hole M.D. was added to the NLM team in January 1989 to play a leading role in UMLS Metathesaurus development and production.

Lindberg was a visionary, but his strategy for advancing toward any large goal was data-driven and incremental. He expected the need for adjustments in response to new knowledge and emerging opportunities, whether in method, technology, or content. During 1985 and early 1986, the NLM UMLS team compared some key biomedical vocabularies and classifications, e.g., NLM's Medical Subject Headings (MeSH), the International Classification of Diseases (ICD), the Systematized Nomenclature of Medicine (SNOMED), to gain a better understanding of the problem the UMLS aimed to solve. In this context, the definition of "key" was *in use* in machine readable biomedical information sources. This early work confirmed that significant differences in the content and structure of terminology systems reflected significant differences in purpose and use. No single vocabulary system was at all likely to meet all anticipated needs.

Based on Schoolman's advice, Lindberg selected the method (Task Order research contracts) for funding the participation of university-based informatics research groups to give NLM more control over evolving major decisions than possible with grant mechanisms. Since NLM would be responsible for long term maintenance of any successful UMLS resources, he needed the final say on their scope and development methods. Lindberg personally enlisted the American Medical Association (AMA) and the College of American Pathologists (CAP) as public allies of the UMLS project, although their corporate views of it would change over time. He also verified that work underway to update the ICD would not reduce the problem the UMLS was intended to address.

Congress added one million dollars to NLM's FY 1986 budget to support the UMLS project. Lindberg allocated an equal amount from NLM's existing research budget. In March 1986, NLM issued a competitive Request For Proposals (RFP) for multiple two-year research and development contracts. The RFP reflected the Library's then-current

thinking about UMLS objectives and strategy, including the probable need to develop at least two new knowledge sources, a Metathesaurus (the word was coined by NLM during the UMLS project) and an Information Sources Map [Endnote 1]. The first two-year contract period was intended to be exploratory, however, and to result in firm decisions about the necessary UMLS components and how to build them, as well as a greater understanding of the context in which they would operate, e.g., medical natural language, existing vocabularies and classifications, machine readable biomedical information sources, and user information needs.

In August 1986, NLM awarded four Task Order research contracts to teams including seven distinguished informatics research groups in five states. Several teams already held NLM-funded informatics training grants. The NLM UMLS team was the eighth group in the sixth state. Humphreys was NLM's technical project officer for the contracts. The list of initial UMLS research participants was a who's who in medical informatics. At least ten were already Fellows of the American College of Medical Informatics elected in its inaugural two years (1984-85), and many who worked on the project would be elected later. The UMLS project was "a distributed national experiment", to use Lindberg's term, and an early U.S. example of a funded "multidisciplinary, multicenter study" in medical informatics research. With no model to follow, NLM and its UMLS contractors proceeded to establish a framework for collaboration, including relatively early use of email via the Internet.[10]

3. Explaining the UMLS Goals and Assumptions

The initial level of confusion about the UMLS goals and general approach may be hard to comprehend today. To those involved in biomedical informatics and data science in the 2020s, the need to retrieve, integrate, and aggregate information and data at scale from disparate machine-readable sources with different terminologies and code sets is obvious. The value of regularly updated multi-purpose resources, whether knowledge sources or programs, to meet this need is apparent. In 1986-1988, however, Lindberg's UMLS ideas were new to many in the informatics field and not very clearly expressed. The majority of potential users were not yet attempting to retrieve information from multiple disparate sources, let alone a mixture of evolving internal and external databases. There were few examples of knowledge artifacts intended primarily for use by system developers as opposed to end-users, and little experience with customizing multi-purpose resources for specific applications. Not surprisingly, the successful UMLS contractors came to the project with differing interpretations of its purpose and potential methods, and different ideas about the terminology problems and priorities NLM should address immediately.

Once decisions about the basic parameters for the initial UMLS Knowledge Sources were made in late 1988, Lindberg and others on the NLM UMLS Team began to publish clearer and more definitive statements about the UMLS goals and assumptions, contradicting some of the misconceptions then circulating.

"The Unified Medical Language System (UMLS) project is … designed to facilitate the retrieval and integration of information from many machine-readable information sources, including descriptions of the biomedical literature, clinical records, factual databanks, and medical knowledge bases. The UMLS project is not an attempt to impose either a single standard vocabulary, a single standard record

format, or a single medical knowledge base on the biomedical community. The UMLS approach assumes that diversity will continue to exist and therefore seeks to provide products that can compensate for differences in the vocabularies or coding schemes used in different systems, as well as for differences in the terminology employed by system users." [14, p.475]

Three additional explicit UMLS assumptions reflected Lindberg's pragmatic views about system development in general. The first was a well-known Lindberg maxim, expressed in this instance as "information systems must be used if they are to improve," [14, p.475]. He expected the new and different UMLS components to begin as relatively simple structures and to go through iterative development with input and feedback from the intended users based on testing and use. "Complexity will be added in subsequent versions as actual use shows it to be necessary" [14, p.475]. The imperative for iterative development with user feedback dictated release of new editions of the UMLS components at least annually. Given their novelty, size, and initial lack of tooling, obtaining input on the early versions from system developers and researchers was difficult. In addition to free worldwide dissemination and internal testing and use, NLM employed various funding mechanisms to promote testing, use, and feedback. This was an unusual practice in the early 1990s, although it became more common later.

The second assumption, "effective information systems must interact with the end user," presupposes the presence of a user of any system employing the UMLS components to verify the interpretation of queries and resolve ambiguities beyond the system's understanding [14, p. 475]. Lindberg did not expect use of the UMLS components to enable information systems to produce perfectly relevant results, as if by magic, based on an initial user query. Early descriptions of how users might interact with systems that used UMLS knowledge imply a greater degree of iteration with individual users than actually became the norm after the arrival of the World WideWeb (WWW). Current systems employing UMLS or other resources to provide linked access to multiple information sources favor strategies designed to reduce individual user effort, although the user is still the final arbiter of what is relevant. These strategies include precomputed links among related information; established connections to specific information sources, e.g., via the Infobutton standard; and shaping current retrieval based on analysis of user search history.

The third assumption was "UMLS development will not be dependent on any projected or possible improvements in the basic information sources to which the UMLS will relate" [14, p. 476]. Lindberg applied this principle to other major NLM initiatives during his tenure. He viewed new and unanticipated developments as inevitable and was ready to take advantage of them when they occurred. He did not, however, commit major NLM resources premised on the future arrival of any specific development over which NLM had no control.

4. Setting General Parameters for the UMLS Metathesaurus and Semantic Network

Decisions about the scope and general structure of the UMLS Metathesaurus and Semantic Network emerged from an intense iterative process, informed by the work and opinions of all UMLS research groups [9, p.5-6]. Early statements about the UMLS project implied possible development of a new vocabulary to which existing terminology

systems would be mapped. While some UMLS-funded work explored structures for a new canonical representation of clinical concepts, Lindberg viewed development of a new clinical vocabulary as inappropriate for NLM ("The Library doesn't have patients"). Creating yet another biomedical terminology seemed counter-productive to the NLM team and too time-consuming as a first step toward the UMLS goal of facilitating retrieval of conceptually related information from multiple machine-readable sources.

Based on previous experience with processing words and terms from machine-readable texts and terminologies, the University of California, San Francisco (UCSF) UMLS Team proposed a different approach: "bootstrapping", or pre-computing, a draft Metathesaurus from existing terminologies and coding systems. The application of advanced computational methods to direct reuse of existing machine-readable vocabulary sources appealed to Lindberg. It struck the NLM Team as a more feasible, scalable, and still useful way forward, provided synonymy was confirmed or established among terms from the different vocabulary sources. In other words, the Metathesaurus would be organized by concept. Methods proposed by UCSF would help domain experts to achieve this. If one source asserted that two medical terms were synonyms or closely related, then those and other lexically similar terms could be collected into a single record for subsequent expert review.

Sample records illustrating the proposed methods and, importantly, a concept organization, were produced for review by all UMLS project participants. The sample records clarified the intent to include in the Metathesaurus all the terms and hierarchical categorizations for each concept from all its vocabulary sources, irrespective of conflicts within or among them. Each vocabulary's hierarchy, for example, was deemed essential to facilitate retrieval from databases indexed or encoded with it. Increasing the degree of unfamiliarity for those working on the project, at that time "concept-based" representations were not widely used in scalable information systems.

Many were skeptical about the value of a Metathesaurus with these parameters and adamant about the need for some level of consistent categorization of all concepts included. Based on their strong recommendations, NLM decided to create a separate UMLS Semantic Network, consisting of high-level Semantic Types or categories, e.g., Medical Device, Anatomic Abnormality, and the sensible relationships among them. Every Metathesaurus concept would be assigned at least one of the Semantic Types. This was an added task requiring domain expert review, but Semantic Type assignment proved to have major benefits for Metathesaurus construction and maintenance, as well as for use of the UMLS, e.g., in natural language processing (NLP).

With these decisions made, an NLM group led by Hole and Lexical Technology, Inc. (LTI), a firm formed by members of the UCSF UMLS team, focused on producing the Metathesaurus. McCray led the development of the Semantic Network, with input from all UMLS research groups. In this case, as in others, Lindberg did not expect perfection, but he did expect increased understanding of the problems involved, quickly produced first versions that showed some promise, and steady improvement in subsequent versions based on feedback from users. In the presence of all of these, he was willing to weather criticism from early users and ignore most comments from non-users.

5. Building the UMLS Metathesaurus

The production of the Metathesaurus was a "Big Data Science" project for its time, requiring substantial computing power for lexical matching and context representation and sophisticated large screen displays to assist domain experts in grasping the semantics and details of source vocabularies. The initial 1990 version had 64,123 concepts and 208,559 concept names from 7 vocabularies, thus dwarfing each of its components. Metathesaurus construction and maintenance was a bi-coastal operation with the NLM team in Bethesda, Maryland and the LTI Team in Alameda, California, so high-speed communications were also essential. At a time when it was unusual, LTI became an Internet node. This enabled sometimes overnight revision of Metathesaurus content when release deadlines loomed. In his dual roles as NLM Director and the first Director of the National Coordination Office of the High-Performance Computing and Communications (HPCC) (1992-1995), Lindberg funded, followed, and highlighted UMLS use of HPCC technology, which became more and more critical to Metathesaurus production as its size and complexity increased [15].

Typical for data science projects, "data wrangling" was a huge challenge for Metathesaurus creation and maintenance. At the time, LTI called it "source inversion" to denote the process of determining the internal semantics of each source vocabulary and transforming its "raw" machine-readable version into a common explicitly tagged representation for use in lexical matching and computing draft Metathesaurus entries. In current data science parlance, the development and ongoing maintenance of the Metathesaurus can be viewed as a largely successful effort to make terminology data more FAIR (findable, accessible, interoperable, and reusable) [16]. These themes were inherent in Lindberg's earliest statements about the UMLS.

All the "source vocabularies" for the Metathesaurus had content worth reusing, but the state of the art in machine-readable representation of terminologies was primitive. Technical formats ranged from simple word processing files to print tapes to databases. In some cases, a printed book was considered the authoritative version; some content visible in print to the human eye, e.g., conveyed by indentations or different type fonts, was difficult, if not impossible, to infer from the machine-readable version. Many sources lacked explicit metadata or explanatory documentation in any form. With the partial exception of MeSH, none had implemented formal change-tracking. As a result, a significant burden placed on Metathesaurus maintenance was the detection and interpretation of changes in new versions of the constituent sources and the invention of better change representation mechanisms.

Metathesaurus development and maintenance raised consciousness about the value of assigning permanent unique non-semantic identifiers, i.e., "the name that never changes", to concepts in terminologies and classifications. When Metathesaurus construction began, if vocabulary sources had unique identifiers, they generally were codes that conveyed the meaning of the concepts to which they were attached. Meanings of codes could change over time if the name changed. In extreme cases, a specific code might be retired and then later reused for a different concept. Codes might misrepresent the meaning of new concepts if inadequate "room" existed for creating new codes. Only one salient aspect of a concept was represented in a meaningful code, e.g., pulmonary tuberculosis as either a lung disease OR an infectious disease, but not both. Based on his experience, Lindberg was highly critical of the practice of relying on codes as the sole indication of biomedical meaning in electronic health data. He favored storage of

biomedical terms, as well as codes, to enable more accurate interpretation of current patients' data by health professionals and of longitudinal data for research.

As became evident, no biomedical terminology systems were strictly organized by concept prior to the production of the Metathesaurus. Under Schuyler's direction, NLM added concept organization, permanent context-free identifiers, and other features to MeSH in 1988/9 to, among other objectives, ease Metathesaurus production and maintenance. Most source vocabularies had one or more "entry terms" pointing to the preferred name or code associated with a concept, but did not express precise distinctions or relationships, e.g., synonymy, among them. Verifying and establishing synonymy among the names and codes in individual source vocabularies was therefore as essential to producing a Metathesaurus organized by concept as was establishing synonymy across different vocabulary sources.

NLM committed to ensuring that each source's view of the relationships among its terms was extractable from the Metathesaurus, i.e., "source transparency" [17]. By contrast, due to competing views of synonymy within its different sources, the Metathesaurus' own concept structure had to represent a single view. A pragmatic approach emerged. The most fine-grained authoritative distinction would "win" over larger-grained aggregates. In other words, if a distinction between two concepts mattered in some biomedical or health-related context, then there would be two concepts in the Metathesaurus [18].

End-user assessments of the coverage of early Metathesaurus versions prompted major revisions - thus proving Lindberg's rule, "use generates improvement." Metathesaurus file structure changed, multiple word and term indices were added, and from 1994 onward, UMLS releases included the SPECIALIST lexicon and lexical tools. Early experiments to determine whether the Metathesaurus embodied specific sets of terms produced variable and often irreproducible results. Often users' publications claimed that the Metathesaurus lacked certain specific content that was in fact present. Adding word, normalized word, and normalized string indices to the Metathesaurus files and including the lexical resources used to generate these indices in the UMLS release immediately improved the comparability of vocabulary matching results and provided the foundation for future tools that simplified UMLS use, e.g., MetaMap [19-20].

Lindberg always left a door open for changes in direction in the face of new knowledge and opportunities. Nevertheless, relatively early decisions about Metathesaurus scope, content, and semantics remain in effect today, despite enormous increases in its size [21]. The 2021 AA version contains 4.4 million concepts and 13,668,045 concept names from 218 vocabulary sources. Important enduring Metathesaurus characteristics include: a scope defined by the combined scope of its source vocabularies; organization by concept; permanent non-semantic concept unique identifiers (CUIs); assignment of high-level semantic types to all concepts; and inclusion and explicit attribution of each source's terms and relationships in a common fully specified format, irrespective of conflicts with other sources.

Precise attribution of the sources of content in the Metathesaurus gradually improved over successive versions [17]. This made change management more tractable. Many producers also made it a sine qua non for UMLS inclusion of their vocabularies (especially those with use restrictions). It supported accurate and efficient exclusion of vocabularies for particular applications and facilitated Metathesaurus updates.

6. Developing the UMLS Semantic Network

The UMLS Semantic Network consists of (1) a set of broad categories, or Semantic Types, e.g., "Pharmacologic Substance", "Disease or Syndrome", "Geographic Area", that provide a consistent categorization of all concepts represented in the Metathesaurus, and (2) a set of useful and important relationships or Semantic Relations that exist between the Semantic Types, e.g., "Causes", "Treats." The hierarchical or "Isa", relationship. e.g., "Geographic Area" Isa "Spatial Concept", enables Semantic Types to inherit properties from their ancestor Types. The most specific type applicable is assigned to each Metathesaurus concept. In an expression Lindberg liked, the Semantic Network is in essence a computer-readable representation of biomedical "common sense," to which each Metathesaurus concept is linked by virtue of its Semantic Type assignment [9].

The development of the Semantic Network differed from the development of the Metathesaurus in several respects. It was not a Big Data project: the first version had 131 Semantic Types and 34 Semantic Relations. Its structure was not novel: it was based on artificial intelligence (AI) theory and practice on knowledge representation for natural language processing (NLP). There was no direct reuse of existing content, but, in line with Lindberg's preferences, its new content was influenced by analyses of relevant "facts on the ground" by UMLS research teams. These included categories in the MeSH tree structures (MeSH has the broadest scope of the Metathesaurus source vocabularies) and relationships represented in clinical knowledge sources, NLP research, and MEDLINE queries and citation records. Importantly, the first public version of the Semantic Network reflected improvements made after a test involving preliminary Type assignments to 30,000 Metathesaurus concepts [22-23].

What was new about the Semantic Network and distinguished it from similar contemporaneous efforts was its very broad coverage [22]. Its scope had to support high level categorization of all concepts in the Metathesaurus source vocabularies. For example, MeSH encompasses a wide range of concepts, e.g., World Health Organization, Medicare, Buddhism, Civil Rights, Life Change Events, Cost-Benefit Analysis. As a result, the Semantic Network was the first "upper-level ontology" for the biomedical domain, with categories applicable to concepts in intersecting domains [24].

As with other UMLS resources, the plan was to add content and complexity to the Semantic Network only as use showed it to be necessary. Lindberg wondered whether the Semantic Network would eventually need more Semantic Types or more Semantic Relations [9]. As shown in the Semantic Network Archive, there was growth in the number of Relations and the number of relationships asserted between Semantic Types during the first decade of UMLS use, but changes have been relatively minor since that time [25]. The current version, stable since 2015, contains 127 Types and 54 Relations. Additions and deletions of Semantic Types cannot be made lightly given the downstream effect on Metathesaurus maintenance. There has been relatively little user demand for more granular Types. Instead, many users prefer to group Semantic Types, e.g., all types for health "problems", to aggregate concepts for various NLP and data mining tasks. In 2001, NLM added "Semantic Type Groups" to the UMLS release to meet this need [26].

Among many other uses, Semantic Types are a quick way to distinguish ambiguous terms, e.g. Sodium (Biologically Active Substance) vs. Sodium (Laboratory Procedure). The assignment of candidate Types to new additions to the Metathesaurus based on the purpose, e.g., disease classification, or hierarchy, e.g., neoplasms, of the source vocabulary avoids incorrect grouping of lexically similar, but semantically different

terms during Metathesaurus updates, thereby reducing work for expert reviewers. The number of under-specified concept names has diminished over time, e.g., "Cold" instead of "Cold Temperature," one of the many improvements in source vocabularies influenced by the UMLS project.

7. Incorporating the SPECIALIST Lexicon and Lexical Programs

In parallel with the early phases of the UMLS project (1986-1990), McCray and the NLM NLP group she formed developed SPECIALIST, a prototype system for parsing and accessing medical text. Lindberg had no specific guiding role on this effort beyond recruiting McCray to establish a linguistics research program at NLM and applauding the results. The SPECIALIST Lexicon and lexical tools were created to provide linguistic knowledge, i.e., lexical information, and rules of morphology, syntax, and semantics, "based on the assumption that systems combining domain knowledge with sophisticated linguistic analysis will lead to improved representation and retrieval of biomedical knowledge" [27, p.103]. Because biomedical language intersects with the standard language, the Lexicon encompassed general (standard) English lexical items, as well as biomedical domain specific lexical items [27]. In addition to other sources of general English and biomedical terms, the NLP group analyzed language in MEDLINE citations and abstracts to identify frequently occurring words and terms for inclusion in the Lexicon. They relied on MeSH as one source of domain knowledge, adding labels to the relationships in MeSH hierarchies which were subsequently incorporated into the Metathesaurus.

When the early versions of the UMLS Knowledge Sources were released, the NLM NLP group became active and sophisticated users, employing them to extend the capabilities and coverage of the SPECIALIST system and Lexicon and providing important feedback and assistance on useful UMLS improvements [28]. Experiments by external UMLS research teams also involved a range of automated lexical matching methods to map other vocabularies and free text to early versions of the Metathesaurus [e.g., 29-31]. The variable results of these experiments demonstrated the need to include word and term indexes in the Metathesaurus. Members of external UMLS teams, notably Columbia and LTI, encouraged NLM to release the SPECIALIST lexicon and lexical tools as part of the UMLS Knowledge Sources and to use them to produce normalized word and term indexes for the Metathesaurus. NLM added the Lexicon and lexical tools to the UMLS release in 1994 [19].

The SPECIALIST Lexicon and lexical programs were the first openly available and regularly updated biomedical lexical resources in English. Their release, both separately and as part of the UMLS Knowledge Sources, provided an unparalleled opportunity for research and development in biomedical NLP. Within a year of their addition to the UMLS Knowledge Sources compact discs, NLM made all the UMLS components available on the Internet from a UMLS Knowledge Source Server. The server had three different client interfaces: a Web interface for browsing and exploring, a command line interface for batch processing, and an application programming interface (API) to enable embedded calls to UMLS resources from external programs [32]. The new access methods made possible by the spread of HPCC technology, in combination with the addition of the lexical components, triggered substantial increases in use of the UMLS resources, particularly in NLP research and development.

8. Considering the Impact of the UMLS

In 1984, Donald A.B. Lindberg M.D. conceived the UMLS. Because it is both an evolving set of artifacts and a set of ideas, it is hard to find, over the ensuing nearly 40 years, a large biomedical information project that has not been influenced by it. Today, as a testament to Lindberg's foresight, the UMLS is infrastructure - heavily used, but not always cited [12,33-34]. As described here, it had no precedent, and, thus, initially, application developers, and their end-users, had difficulty applying it. But, as Lindberg often said, "Things that are used tend to get better." Slowly the field adopted either the UMLS artifacts themselves, its content, such as the synonyms, or its ideas, such as concept-based representations. While computers still struggle to "understand" biomedical meaning usefully, most would agree that Lindberg's vision and development approach enabled substantial progress in this important area.

The UMLS remains useful because Lindberg's 1984 expectations for the future in which it would operate proved to be highly accurate: exponential growth in biomedical and health data; great advances in computing and communications; increasing importance of molecular biology and genetics in research, knowledge discovery, and health care; greater patient interest in, and access to, health information; and no single standard language capable of meeting all biomedical and health needs, despite UMLS-aided progress toward clinical terminology standards [35]. The UMLS was initially ahead of its time and therefore ready for use when the future Lindberg envisioned arrived.

Endnote

[1] NLM released an experimental UMLS Information Sources Map (ISM) from 1991-1997. It ceased when Internet search engines and the World Wide Web changed many aspects of the problem of creating machine interpretable metadata for digital information sources. Greater integration and better discovery and linking mechanisms reduced the problem for NLM's own information resources. Nonetheless, it is an unsolved problem and continues to be the focus of current work, e.g., Alper BS, Flynn A, Bray BE, et al. Categorizing metadata to help mobilize computable biomedical knowledge. Learning Health Systems. 2021 DOI: 10.1002/lrh2.1027

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Don Lindberg and the Creation of the National Center for Biotechnology Information

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Abstract. The highest priority new initiative resulting from the 1985-86 National Library of Medicine Long Range Planning exercise initiated by NLM Director Dr. Donald A.B. Lindberg was the creation of new information resources and services related to molecular biology and genetics, termed "biotechnology information". Beginning with existing NLM resources and research projects associated with molecular data, and with Lindberg's enthusiastic support, the institution launched a Congressionally-mandated Center that has become an essential part of 21st century biomedical science.

Keywords. Donald A.B. Lindberg, U.S. National Library of Medicine, National Center for Biotechnology Information, Human Genome Project, Genomics.

1. Background

The genesis of the U.S. National Library of Medicine's (NLM) National Center for Biotechnology Information (NCBI) was intimately interwoven with the 1985-86 NLM Long Range Planning effort that was one (and perhaps the most notable) of NLM Director Dr. Donald A.B. Lindberg's signature initiatives in his first years at NLM. Shortly after he arrived as the newly appointed NLM Director in August of 1984, and with the endorsement of L. Thompson Bowles M.D., Ph.D., the chairman of the NLM Board of Regents, who had been appointed that same month, Lindberg convened more than 120 professionals in a visioning exercise that asked them to imagine what NLM's world would look like in 20 years and what its future services should be. They were also charged with identifying 10-year milestones on the path to that 20-year future, and describing the challenges and impediments to be faced in realizing that vision. Most importantly, participants were asked to identify "windows of opportunity" for the institution, for new programs and resources that could be started immediately and could be finished within five years. As part of the planning process, all involved were reminded of the humbling observation that most long range planning efforts systematically overstated what could be achieved in five years, while they fell short of actual achievements by 10 years, and completely missed key innovations and social

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changes that would become the real determinants of the future two decades later. With the luxury of now more than 35 years of hindsight, those NLM long range planners can take some pride in being approximately correct far more often than they were precisely wrong.

The Long Range Planning effort under Lindberg's direction was divided into five topic areas: building and organizing the Library's collection; locating and gaining access to medical and scientific literature; obtaining factual information from data bases; medical informatics; and assisting health professions education through information technology. Seventy-seven professionals with expertise across these areas were appointed to five planning panels that each met several times over a year beginning in the Fall of 1985. The draft Long Range Plan was reviewed and approved by the NLM Board of Regents in January 1987 and became an active roadmap for the Library's major programs for the ensuing two decades and beyond [1].

Of special importance to the creation of NCBI were the discussions and recommendations of Panel 3: Obtaining factual information from data bases. The 16 individuals appointed to this panel included two current and one future Nobel laureates: Joshua Lederberg, Allan Maxam, and Richard Roberts. Lederberg had won the 1958 Nobel prize in Physiology or Medicine for "discoveries concerning genetic recombination and the organization of the genetic material of bacteria" [2]. Maxam, along with Walter Gilbert, Frederick Sanger, and Paul Berg, had shared the 1980 Nobel prize in Chemistry for devising a technique to sequence DNA [3]. Roberts shared with Phillip Sharp the 1993 Nobel prize in Physiology or Medicine for demonstrating how the RNA produced by transcription of DNA can be divided up into introns and exons, after which the exons can be joined together [4]. The background and expertise of these three researchers in molecular genetics heavily influenced the depth of the planning discussions and the vision for NLM's future.

One event in particular profoundly influenced Don Lindberg and may justifiably be considered a turning point in NLM history. During one of the early face-to-face Planning Panel 3 meetings, with Lindberg present as an observer, Allan Maxam gave a spontaneous "chalk talk" on the challenges confronting researchers who were attempting to understand the molecular underpinnings of health and disease. He began by listing commonly used research databases in molecular biology and genetics, organized in a size hierarchy that went from intact cells and tissues down through individual DNA and RNA nucleotides, and included small molecules that modulate the production and functioning of genes and their protein products. The diagram he drew (Figure 1), which with refinements was published in the Long Range Plan, came to be known within NLM as the "Tower of Babel" picture, for it highlighted the lack of naming consistency and interconnections among research databases constructed by different organizations. The incompatibility of these closely related scientific resources thwarted a researcher's ability to use similarities and insights from one database to explain findings recorded in another, and contrasted with the scientific literature where a single experiment might produce data that was then included in several disparate databases.

Biotechnology Knowledge Bases

Cells and Tissues
ATCC Cell/Tumor Bank
Hybridoma Data Bank

Cell/Tissue Protein Arrays
Proteus Technologies, Inc.
Protein Databases, Inc.

Chromosome Libraries
Los Alamos/Livermore Banks
Cytogenetic Maps
Cytogenetics Database

Genetic Maps
Human Gene Library (Yale)
Oncogene **Human Gene Map (SHG)**
Mouse Map (Jackson Labs)
Genetic Maps (NIH)

Restriction Maps (enzyme cutting sites)
Genetic Maps (NIH)

Gene Maps
Genetic Maps (NIH)

DNA Sequences
GenBank (NIH)
EMBL Bank (Europe)

mRNA Sequences
GenBank (NIH)
EMBL Bank (Europe)

Protein Sequences
Protein Resource (NBRF)
Japan Protein Bank

Protein Structures (e.g. HIV-1 Protease)
Brookhaven X-Ray Databank
Crystallographic Data Centre

Mutagens/Carcinogens/Drugs (e.g. AZT)

Figure 1. Biotechnology Knowledge Bases, adapted from Allan Maxam's Long Range Plan presentation, 1987 [5].

Maxam illustrated the promise of molecular biology computing with a story from the research literature of the time related to oncogenes, which are genes that can induce cancerous behavior in cells. He noted that databases such as GenBank that contain DNA sequences enable researchers to use computer-based analysis to calculate the similarity of genes to one another, sometimes providing powerful and unexpected insights. Such was the case with the v-sis "proto-oncogene" that was found by computer matching in the early 1980s to be nearly identical with a normal growth and development gene called "platelet derived growth factor." This finding gave rise to the key biological insight that cancer-causing genes might in some cases be normal genes simply switched on at the

wrong time. Maxam noted that this ability to "reason by analogy" often depended upon findings at different levels of the biologic hierarchy depicted in his diagram, and that there were few if any automated tools capable of finding such correlations across the dozens of databases storing molecular information and its interpretations.

Don Lindberg was immediately and enduringly impressed by this presentation and the opportunity it portrayed for NLM to help guide, structure, and link related scientific resources in pursuit of better understanding human health and disease. The "oncogene story" was included in the planning panel's report, which included the following observations [6]:

"The general area of biogenetics is moving ahead rapidly. Serious proposals have been put forward to sequence the entire human genome and to map active chromosomal regions for each tissue type in different organs systems…. The research-oriented information systems currently in place are adequate to ask low level questions: Find the degree of similarity between base-pair sequences. The next questions are: What do the differences mean? Current data bases are being used to support modeling and theory, but the tools are very primitive, and no methods exist for automatically suggesting links across levels. There is a vacuum in the area of research into ways of using information by interconnecting various levels…. Currently, no organization is taking the lead in promoting keys and standards by which the information from the related research data bases in the accompanying [Tower of Babel] figure can be systematically interlinked or retrieved by investigators."

The report went on to note "A singular and immediate window of opportunity exists for the Library in the area of molecular biology information. Because of new automated laboratory methods, biological data are accumulating far faster than they can be assimilated into the scientific literature. The problems of scientific research in the field of molecular biology are increasingly problems of information science."

The Long Range Plan included the following Recommendation:
"3.2.1. Immediately establish an intramural and extramural program for biotechnology information. The intramural component should be a National Center for Biotechnology Information, to serve both as a repository and distribution center for the growing body of knowledge and as a laboratory for developing new information analysis and communications tools essential to continued advancement in this field…. Because of the technical complexity in this scientific area and the expectation that data production will increase by a thousand times in the next five years, a major new activity is required." Lindberg's own words on the subject were included as a Preface to the Plan: "Of the numerous initiatives the plan proposes … one in particular stands out. This is the "window of opportunity" presented to the Library in the field of molecular biology and biotechnology. Attention to this opportunity - through the provision of advanced information handling services - will permit NLM to contribute significantly to discovery of new principles and treatments by health-care professionals and scientists." [1]

By the time the Long Range Plan was published, Lindberg was already taking steps to implement its key recommendations. One of these steps was appointing a new director of the Lister Hill National Center for Biomedical Communications (LHNCBC), which since its 1968 creation had been the intramural research and development division of the Library. The previous director, Dr. Richard B. Friedman, had left the NLM for a faculty appointment at the University of Wisconsin in 1984, shortly before Don Lindberg's arrival.

Lindberg recruited Daniel Masys M.D. to the LHNCBC director position in the spring of 1986 by inviting him to an informal visit to the NLM Director's office. He

presented the proposition that "we cannot make the progress needed in biotechnology information without you." Masys was at that time the chief of the International Cancer Research Databank branch of the National Cancer Institute (NCI). He had participated in the Long Range Plan exercise as an appointed member of the Factual Data Bases panel. As a physician trained in hematology and medical oncology, Masys was familiar with the nascent and rapidly evolving science of "molecular medicine" and had come to NIH to help design the NCI's Physician Data Query (PDQ) computer system. PDQ was a continuously updated online resource of cancer information for both physicians and patients [7]. The offer of the LHNCBC directorship was readily accepted. The personnel action was straightforward because Masys was a commissioned officer in the U.S. Public Health Service and his NLM appointment was simply a re-assignment.

2. Building on Existing Programs and Staff

The Long Range Plan recommended a $9.7 million annual budget increase devoted to biotechnology information services and 34 additional full time equivalent NLM personnel [1]. Such a significant expansion could not be achieved by reallocating existing budgets, and would necessarily involve supplemental appropriations by the U.S. Congress. That notwithstanding, the work needed to begin immediately. The obvious and immediate path forward was to organize current staff and existing information resources and research projects to become a platform for future growth and enhancement.

The largest and most widely used of NLM's resources was the MEDLINE database of bibliographic citations and their associated index terms and author abstracts. Essentially all factual databases in molecular biology included citations to the published articles that reported the data included in each factual database record. This feature gave NLM a powerful mechanism for linking disparate research databases. At Don Lindberg's direction, an early enhancement to MEDLINE added the "reverse pointer" of the external database name (e.g., GenBank) and the external database record unique identifier to MEDLINE citation records. With this linking data, both human users and computer programs could begin with a search of the scientific literature in MEDLINE and then navigate to the actual data reported by the article in the externally linked data base.

NLM had the good fortune of existing intramural research projects conducted by LHNCBC staff that had a focus in clinical and molecular genetics. The most notable was the Online Reference Works project whose goal was to produce electronic authoring systems for complex publications such as biomedical textbooks. The model envisioned a "scholar's workstation" that helped an author write and maintain a large and evolving corpus of knowledge, output phototypesetting files that would generate the printed copy of the monograph, and serve also as a searchable database of full text [5].

At the same time, the Welch Medical Library at Johns Hopkins had contacted NLM for assistance on behalf of Victor McKusick M.D., the author of *Mendelian Inheritance in Man* (MIM), an 1,800 page, comprehensive compendium of information of human genes and genetic phenotypes that was in its sixth edition in the early 1980s [8]. Dr. McKusick was heroically attempting to edit and maintain the text personally by reading the newly published literature every day and using manual, paper-based notations to update the monograph. Using MIM as its test case, in 1984 the Online Reference Works project created a multimedia system called IRx (Information Retrieval Experiment) that contained both text and images such as gene maps and clinical photos of genetic diseases.

This work preceded the Long Range Planning exercise and provided a fertile research and development environment for new methods of linking genetic-related data [9].

Systems such as the IRx prototype were possible only because of the technical expertise of LHNCBC staff, and the project benefitted from the leadership of an individual who would become one of NCBI's senior leaders. Dennis Benson Ph.D. was a neuroscientist working as a Research Associate at Johns Hopkins School of Medicine Department of Biomedical Engineering, conducting research in auditory neurophysiology. His work involved extensive programming of laboratory instrumentation. He came to NLM's Lister Hill Center in January of 1980 and was the technical lead for the IRx project when the request for help with MIM came. As a result, he was already immersed in the world of computers and genetics when the Long Range Plan was completed.

Drs. Masys and Benson, with Dr. Lindberg's boundlessly enthusiastic support, became the early "biotechnology information project" team as soon as Masys arrived in July 1986. They viewed their principal tasks as outreach to better understand the needs of researchers, and increasing the visibility of NLM's newfound interest in advancing molecular genetics and biotechnology-related research. This mission led to much travel and participation in domestic and international scientific meetings, where they would present NLM's current and planned services.

At one of these events, another fortuitous connection occurred that would mold NCBI's programs. Masys and Benson gave a presentation at a 1986 workshop on "Genes and Computers" held in Waterville Valley, New Hampshire. At the participant lunch that followed, graduate student James Pustell introduced himself and expressed an interest in NLM's plans. Pustell was studying for his Ph.D. in molecular biology with Dr. Fotis Kafatos at Harvard. An energetic self-starter and practitioner of what would become widely known as "bioinformatics", Pustell had written a suite of molecular sequence analysis programs for microcomputers that were marketed by International Biotechnologies, Inc. [10]. A natural "meeting of the minds" occurred that day, which eventuated in Pustell (later to become James Ostell on the occasion of his marriage to Kate Oster) becoming one of the founding senior leaders and guiding lights of NCBI.

As noted in the NLM Long Range Plan, there was a growing conviction among scientists that a project to sequence the entire human genome would soon become both feasible, due to new automated sequencing technologies, and immensely valuable in understanding human health and disease. In October 1986, NIH Director James Wyngarden convened an NIH Director's Advisory Committee meeting on the role that NIH should play in a federally-supported Human Genome Project [11]. NLM was represented by Drs. Lindberg (meeting co-chair), Benson, and Masys, who presented a vision of NLM assuming a central role in managing the data arising from such a project, including the possibility of NLM taking over management of the GenBank DNA sequence database. The response from the director of the National Institute for General Medical Sciences, at that time the GenBank sponsor, was emblematic of the organizational challenges to be faced: "Of course, you don't want librarians taking care of gene sequences." It was an example of the common lack of appreciation that NLM was no ordinary medical library. On the contrary, many on NLM's staff were doctoral level scientists who were trained in the fields of medical and biological information sciences.

The first molecular biology research tools implemented at NLM were hosted on a server computer within the Lister Hill Center. It provided a simple text-based menu interface for searching several databases shown in Figure 1, and analysis tools for

nucleotide sequence comparisons and alignments that could be used on the record sets retrieved from those databases. Improving researchers' awareness of and skills in using computerized analysis was (and remains) an important component of the overall NLM biotechnology information program. To this end, NLM began collaborating with other NIH institutes and hosting onsite hands-on workshops in LHNCBC's Educational Technology Branch classrooms.

One series of these educational programs was taught by David Lipman M.D., a researcher in the Mathematical Research Branch of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). As these NLM programs were starting, Lipman was already an internationally prominent developer of methods for sequence database searching and determination of molecular sequence similarity, including the Wilbur-Lipman algorithm in 1983 and FASTA search in 1985 [12-13]. With Lipman's participation in designing and implementing analytic programs, the senior leadership team was now in place to establish NCBI as a global resource for molecular biology information.

3. The Legislative Road to Creation of NCBI

Don Lindberg and NLM Deputy Director Kent Smith were well equipped to confront the challenges of creating new programs whose size and resource needs would require additional authorization and appropriations by the U.S. Congress. Lindberg had a natural talent for communicating complex scientific issues in ways that members of Congress and their staffs easily understood, and an ability to give public testimony in congressional hearings that conveyed the public benefit to be gained by new programs, while adhering to federal agency restrictions that prohibited employees from advocating for larger appropriations.

Every piece of new legislation also needs legislative champions, and NLM benefitted from the longstanding friendship between one of its employees, Frances Humphrey Howard (sister of Hubert Humphrey, U.S. Vice President from 1965 to 1969), and Claude Pepper (D-FL), who was a U.S. Senator (1936-1951) and a Congressman (1963-1989). A vocal advocate for medical research and particularly the health and welfare of the elderly, Pepper learned of the proposed Human Genome Project and viewed it as a "Manhattan Project" for health. The legislative process also benefitted from the outreach and educational efforts of the newly-formed "Friends of the National Library of Medicine".

In 1986 and 1987, Pepper introduced bills to create a National Center for Biotechnology Information located within NLM. With the help of colleagues in the House and Senate, his bill was incorporated into the NIH reauthorization legislation known as the Health Omnibus Extension Act (Public Law 100-607), which was signed into law by President Ronald Reagan on November 4, 1988 [14].

The mission given to NCBI in its founding legislation was the following:

"(1) design, develop, implement, and manage automated systems for the collection, storage, retrieval, analysis, and dissemination of knowledge concerning human molecular biology, biochemistry, and genetics;

"(2) perform research into advanced methods of computer-based information processing capable of representing and analyzing the vast number of biologically important molecules and compounds;

"(3) enable persons engaged in biotechnology research and medical care to use systems developed under paragraph (1) and methods described in paragraph (2); and

"(4) coordinate, as much as is practicable, efforts to gather biotechnology information on an international basis."

Another key meeting took place during this time. With Dr. Lindberg's concurrence and blessing, Drs. Masys and Benson walked over to the intramural offices of the NIDDK Mathematical Research Branch, and made the same proposition to David Lipman that Lindberg had made to Masys several years earlier: "We cannot make the progress needed in molecular biology and bioinformatics without you." At that point, Lipman agreed only to discuss the opportunity with Lindberg. But the rest, as the saying goes, is history.

Lipman accepted the newly created position of NCBI director in 1989. His personnel action was as straightforward as for Masys, since he too was a commissioned officer in the U.S. Public Health Service, and could simply be reassigned with the concurrence of both NIH institutes. With Lindberg's support and encouragement, Lipman formed his initial senior leadership team: Dennis Benson, James Ostell, and David Landsman, Ph.D., who was at the time an intramural research scientist at NCI.

NCBI became not only a global resource for molecular biology and genetics, but also a brain trust for the redesign and modernization of NLM's other services, including MEDLINE, its flagship literature resource. NCBI began with the subset of MEDLINE records linked to factual databases in biotechnology such as GenBank, and transformed the MEDLINE unit record design into a relational data model that enabled use of highly scalable relational database management systems. This redesign was then extended to the entire MEDLINE citation collection, and with a web-compatible search interface became the basis for PubMed, a system that beginning in 1997 provided free public access to MEDLINE. As it gained technical expertise, NCBI's Information Engineering Branch branch, led by Jim Ostell, created and deployed internet accessible systems that could process thousands of simultaneous queries *per second*. This made the staff highly valued consultants for essentially all of NLM's online information services.

For 28 years, until retiring in 2017, Lipman and his fellow NCBI leaders translated NLM's interest in advancing molecular science into tangible and widely used resources and tools for researchers worldwide. By all measures, the organization has exceeded the goals originally envisioned by Don Lindberg and the Long Range planners, and its services have become woven into the fabric of 21st century science, continuing to catalyze biomedical research on a global scale.

Upon Lipman's retirement, James Ostell was appointed NCBI's second director, taking over a staff that had grown from less than a dozen when Lipman, Benson, Ostell, and Landsman started, to more than 700. Ostell retired in 2020 after 32 years at NCBI. As of this writing, Dennis Benson, in his capacity as NCBI Deputy Director and with 41 years of NLM service, and David Landsman, with 32 years as Chief of the NCBI Computational Biology Branch, are the organization's most experienced leaders.

Choosing to make the creation of NCBI the highest priority of the original NLM Long Range Plan was distinctively Don Lindberg: Recognize the right idea at the right time, and create programs and organizations that grow and are sustainable over time. The long tenure and sustained institutional loyalty of NCBI's founding leaders has also been a testament to Don Lindberg's ability to recognize talented individuals, recruit them for important institutional missions, and then do his best to provide them with both the resources and the freedom they needed to manage their programs in whatever way they

found most effective. Lindberg's style of "trust and delegate" informed his interactions with NLM senior staff throughout his 31 years as NLM Director.

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Don Lindberg, High Performance Computing and Communications, and Telemedicine

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Abstract. From 1992 to 1995 Donald A.B. Lindberg M.D. served concurrently as the founding director of the National Coordination Office (NCO) for High Performance Computing and Communications (HPCC) and NLM director. The NCO and its successors coordinate the Presidential-level multi-agency HPCC research and development (R&D) program called for in the High-Performance Computing Act of 1991. All large Federal science and technology R&D and applications agencies, including those involved in medical research and health care, participate in the now-30-year-old program. Lindberg's HPCC efforts built on his pioneering work in developing and applying advances in computing and networking to meet the needs of the medical research and health care communities. As part of NLM's participation in HPCC, Lindberg promoted R&D and demonstrations in telemedicine, including testbeds, medical data privacy, medical decision-making, and health education. That telemedicine technologies were ready to meet demand during the COVID-19 pandemic is testament to Lindberg's visionary leadership.

Keywords. Donald A.B. Lindberg, High Performance Computing, U.S. National Library of Medicine, Telecommunications, Telemedicine.

1. Historical Background

In 1944, President Franklin D. Roosevelt wrote to Vannevar Bush DEng., head of the federal Office of Scientific Research and Development, and asked for recommendations for the post-World War II world. Dr. Bush's 1945 response is the report "Science – The Endless Frontier" [1]. For "the war of science against disease", Bush recommended that "the Government should extend financial support to basic medical research in the medical schools and universities." The three other areas about which Roosevelt asked were scientific knowledge, aiding public and private research, and scientific talent. The 1950 creation of the National Science Foundation (NSF) traces its roots to Bush's report.

Federal agency support for research and development (R&D) of advanced technologies has been a highly visible part of the American scene since the 1957 launch of Sputnik, the Russian satellite that put our nation on notice that it was no longer the unquestioned global leader in science and technology. In the public eye, the leading federal science agencies associated with the ensuing effort to re-establish our pre-eminence in these domains include NSF, the National Aeronautics and Space Administration (NASA) and the Department of Defense's (DoD) Defense Advanced

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Research Projects Agency (DARPA) (both established in 1958), and the Department of Energy (DOE), which was established in 1977 by consolidating defense and civilian programs. Less visible Federal efforts include those by the National Security Agency, formed in 1952, which continued the codebreaking it had begun during World War II.

U.S. government support for advanced computing in the 1950s and 1960s slackened in the 1970s. When Donald A.B. Lindberg M.D. arrived at NLM in 1984, the Department of Health and Human Services (HHS) and its lead research organization, the National Institutes of Health (NIH) (roots date to 1887), were notably absent in the public perception of federal agency leadership and sponsorship of advanced computing. While appropriately and correctly viewed as an agency focused on health-related biological discovery and medical treatment research, the truth is that NIH also had been providing extramural support for R&D in biomedical computing and telecommunications since the 1960s. The NIH Computer Research and Biomathematics Study Section, a standing grant review committee, included Don Lindberg among its appointed members from 1967 to 1971. Notable achievements of the first several decades of NIH support included:

- Creation of the Massachusetts General Hospital Laboratory of Computer Science (LCS) in 1964 by G. Octo Barnett, M.D., a physician pioneer in the development of clinical computing. To meet the need for a compact data management system adapted to the special characteristics of medical data, LCS developed the "Massachusetts General Hospital Utility Multi-Programming System"—MUMPS (now called simply M), which grew to become an essential component of many public and private systems managing health information in the United States and worldwide [2].
- The SUMEX-AIM project (Stanford University Medical Experimental computer for Artificial Intelligence in Medicine) was a national computer resource funded by NIH between 1973 and 1992 with a dual mission to promote applications of artificial intelligence computer science research to biological and medical problems, and create network-based collaboration and computer resource sharing [3]. Its creation coincided with Don Lindberg's appointment to the Stanford University President's Committee on Computer Science in 1972, and his service as chairman of the SUMEX-AIM national advisory committee from 1975 to 1984.
- The development of the PROPHET system from 1965 to 1985, championed by William Raub, Ph.D., who became NIH deputy director in 1986. The system consisted of a large time-sharing computer connected over telephone lines to display terminals in medical school laboratories, hospitals, and pharmacological research centers. It provided a computing environment tailored to deal with chemical and biological information and its analysis [4]. PROPHET was the first large scale effort to provide NIH-supported computing tools for life sciences researchers at their home institutions.

Each of these efforts could be considered "high performance computing" of their times, since this term has always been relative to whatever "ordinary performance computing" existed contemporaneously as a commonly available set of tools and resources. No clear boundary separates high performance computing and telecommunications from the spectrum of analogous commercially available devices, applications, and services, though the label is commonly reserved for systems that exceed commodity level performance by at least several orders of magnitude.

In 1984, the Division of Computer Research and Technology (DCRT) was the focal point for intramural computing at NIH. After NIH acquired its first digital computer as

an experimental device in 1958, DCRT was established in 1963 and its first director, Arnold W. "Scotty" Pratt M.D., was named in 1966. Under Pratt's leadership, DCRT built a campus computing infrastructure focused on time-shared mainframe and minicomputer hardware and software with a locally developed mainframe system called WYLBUR that supported administrative and scientific applications in NIH intramural labs, centers, and institutes [5].

With the completion of the 1985-1986 NLM Long Range Plan and setting of biotechnology information resources and services as a high priority, Dr. Lindberg oversaw the enhancement of NLM's capabilities to serve new, computationally intensive activities such as gene sequence comparisons and alignment of macromolecules. In 1987, the Lister Hill National Center for Biomedical Communications (LHNCBC)—NLM's existing computer R&D division where the new molecular biology tools and services were first created—established a T-1 (1.5 megabits per second) data network line to the National Cancer Institute's (NCI) Advanced Scientific Computing Laboratory in Frederick, Maryland. That connection provided access to several scientific computers more powerful than NLM's own machines, including a Cray X-MP 2 supercomputer, which at the time was approximately 400 times faster than LHNCBC's VAX servers. It could execute 900 million floating point operations per second (FLOPS), or 90 percent of one gigaFLOP. Apropos of the evolving and relative nature of high-performance computing, as of this writing, current generation Graphics Processing Unit (GPU) cards for gaming PCs now routinely provide up to 20 trillion FLOPS (teraFLOPS) performance, which is approximately 20,000 times faster than the speed of the multi-million-dollar 1987 Cray supercomputer, at retail prices under $2,000.

Don Lindberg's vision and conviction were that NLM should become a world leader in promoting and supporting advanced computing and telecommunications to realize its congressionally mandated role as an archive and distribution point for biomedical literature, data, and scientific knowledge in its many forms [6]. This global view of the opportunities and challenges presented by information technologies had been nurtured by his own career achievements and by serving on the National Academy of Sciences' Computer Science and Engineering Board from 1971 to 1974 and on NLM's Biomedical Library Review Committee from 1976 to 1980.

With his extensive prior experience on academic, professional society, and government advisory committees, Lindberg sought opportunities for NLM and NIH to engage in inter-agency computing and telecommunications collaborations. Part of the White House Office of Science and Technology Policy (OSTP), the Federal Coordinating Council for Science, Engineering and Technology (FCCSET), which had been established by Public Law (P.L.) 94-282 in 1976 to advise the President on science and technology matters and to coordinate federal science and technology efforts, provided one such opportunity [7]. The OSTP Director chaired the FCCSET, which included heads or their deputies from 13 federal departments and agencies involved in science and technology. Federal agency participation in FCCSET initiatives was voluntary. As a federal science agency, NIH had an open invitation to participate in cross-agency meetings and projects, about which the NIH Office of the Director informed Lindberg. The FCCSET was succeeded by the National Science and Technology Council.

In 1987, Lindberg assigned Daniel Masys M.D., director of NLM's LHNCBC, to attend the regular monthly meetings of a nascent High Performance Computing and Communications (HPCC) Working Group of FCCSET's Committee on Physical, Mathematical, and Engineering Sciences (CPMES). That Working Group provided both

a conduit for understanding other agencies' R&D efforts and a podium for presenting health-related "Grand Challenges," i.e., important and difficult-to-achieve usage scenarios, as program goals. These biomedical research and healthcare "use cases" became a prominent feature of the interagency HPCC effort and were incorporated into the legislative record supporting passage of the High-Performance Computing Act in December 1991. Masys was subsequently named the NIH representative to the Working Group and served in that capacity until 1994 when he retired from federal service.

2. The HPC Act and the HPCC Program

FCCSET/CPMES published HPCC Grand Challenges reports to supplement the President's Fiscal Year 1992 and 1993 Budgets [8-9]. They documented DARPA, DOE, NASA, NSF, the Department of Commerce's National Institute of Standards and Technology (NIST) and its National Oceanic and Atmospheric Administration (NOAA), the Environmental Protection Agency (EPA), and NIH/NLM programs and plans. Lindberg kept his vow, made after the Global Change Research Act became law in 1990, that NLM would be explicitly included in any future multi-agency R&D program that had medical and human health impact. 70,000 copies of the 1993 report were printed, and it was said that "everyone" in Washington DC carried one.

Senator (later Vice President) Al Gore (D-TN) shepherded the High-Performance Computing (HPC) Act to passage, starting with the Supercomputer Network Study Act of 1986 [10]. That Act required OSTP to "report to the Congress on fiber optic networks … to improve communications among supercomputer centers and users." The resultant "A Research and Development Strategy for High Performance Computing" reported agency views about supercomputer access, leadership, and research [11]. Between 1988 and 1991 seven HPC bills were introduced, there were seven amendments in the form of a substitute, and there were ten days of public hearings. NLM was mentioned in some versions of the bill, but the HPC Act calls for HHS and six other departments plus three independent agencies to report their HPCC programs and activities.

Dr. Masys testified at one such hearing, in September 1989 [12]. He described recent NLM computing and networking history. NLM had computerized the bibliographic Index Medicus database in 1964; had in 1971 created MEDLINE to make that database "available for on-line searching over public computer networks;" and by 1989 had 38 more databases online as part of MEDLARS (Medical Literature Analysis and Retrieval System), "the largest and most widely-used biomedical computing system in the world." NLM researchers were then connected via DoD's research-and-education-only network to NCI's Cray. Masys stated that biology and medicine would need to understand and transmit images and videos, which was not feasible over the networks of those days; modeling protein folding for analyzing disease-causing agents was too slow on supercomputers of the day; and research in computerized tomography and magnetic resonance imaging required advances in both computing and networking. In answer to a question about how to accelerate progress, he said that vocabulary, language, and data interchange standards were needed, and cited NLM work on a Unified Medical Language System (UMLS).

In the end, the HPC Act of 1991 made HPC a Presidential-level initiative, with the Director of OSTP responsible for interagency coordination and annual reports to Congress [13]. The Act calls for an advisory committee to assess the program. It assigns agency responsibilities and authorizes appropriations from "sums otherwise authorized

to be appropriated." It calls for annual reports on any funds going to non-U.S. entities, and for a study on a supercomputer agreement with Japan.

OSTP established the HPCC Program and the National Coordination Office (NCO) for HPCC in 1992. The Program had four components—and major efforts:

- High Performance Computing Systems—parallel computing systems
- National Research and Education Network (NREN), which became the Federally-funded part of the Internet—gigabit per second networks and applications
- Advanced Software Technology and Algorithms (ASTA)—parallel algorithms, systems software, software tools, applications software
- Basic Research and Human Resources (BRHR)—university-based research, education, training, and curricula

NLM categorized its HPCC investments as follows:

- NREN: Medical Connections to academic medical centers, UMLS distribution, Internet access to image archives, browsing three-dimensional images
- ASTA: Visible Human Project
- BRHR: Medical Informatics training grants

3. Lindberg Serves as HPCCIT Subcommittee chair and Director of the National Coordination Office for HPCC

In August 1992, OSTP Associate Director Eugene Wong, Ph.D., invited Dr. Lindberg to the Old (now Eisenhower) Executive Office Building (EOB). Lindberg wondered aloud to Kent Smith, his deputy, what "we" had done wrong. It was just the opposite. Upon his return from that meeting, Lindberg asked his executive assistant Pat Carson to cancel an extensive international trip so that he could devote his efforts to standing up the NCO. The cancellations took days.

It was said that a key reason Don Lindberg was asked to chair the FCCSET/CPMES HPCCIT (HPCC and Information Technology) Subcommittee and be NCO Director was that he represented an applications agency and not one of the "big four" technology agencies — DARPA, DOE, NASA, and NSF. Promoting grand challenge applications that could benefit from HPCC technologies, and not just the technologies themselves, was in fact key to passing the HPC Act. And the big four agencies considered themselves HPCC equals. Also, Lindberg was the only active HPCC agency principal with an international reputation. The HPCC community was flattered that someone of such prominence was asked to be the founding NCO Director.

In 1993, the Program added a fifth component, Information Infrastructure Technology and Applications, to develop the technology base for a National Information Infrastructure and to work with industry to develop and demonstrate prototype National Challenge applications to complement Grand Challenges [14].

Between 1992 and 1995, Lindberg brought health and medicine organizations into the HPCC Program: NIH's National Center for Research Resources, DCRT, and NCI's Biomedical Supercomputer Center; the Agency for Health Care Policy and Research; the Department of Veterans Affairs; and the Department of Education. Dr. Masys was the NIH HPCC coordinator. The HPCC Program's FY 1996 annual report documented dozens of Grand Challenge and National Challenge applications [15]. The medical and health care grand challenges spanned biomedical imaging, molecular biology, and

molecular dynamics, and included NLM's Visible Human Project. National challenges included digital libraries, in which NLM reported MEDLARS and UMLS.

Lindberg took special pride in three specific HPCCIT meetings. Because the Presidential advisory committee authorized by the HPC Act had not yet been established, only one meeting with any particular private sector constituency was allowed. The first meeting was with directors of supercomputer centers, the second with independent software vendors, and the third with representatives from the telecommunications industry. Participants were asked to discuss their views, needs, and recommendations about the HPCC Program. These meetings typified the cooperative, collaborative relationships across HPCC agencies, industry, and universities.

The NCO was a lean operation. Three people were detailed from NLM: Pat Carson (then Jean Diehl after Carson went back to NLM), Charles Kalina as HPCCIT Executive Secretary, and a staff assistant. Cal Ramos was detailed from NASA and Sally Howe, Ph.D., from NIST. Space on B1 (B for basement) of LHNCBC's Building 38A was outfitted for a large meeting room, a small meeting room, and offices. The HPCC Program had an early web site, and the NCO had a library and a librarian. Lindberg spent mornings in his NLM office on the mezzanine of NLM's main Building 38 and afternoons at the NCO. A sign of the workload: he lost weight.

The HPCCIT Subcommittee met monthly. The NCO prepared detailed agendas and handouts with activity reports, invited speakers, and set up a long table for food — nutritious, as requested, and chocolate for the chair. The often more than 40 agency people who attended delighted in seeing each other and planning next steps. As agency representatives and alternates changed, Lindberg cordially welcomed newcomers, introducing them with spot-on comments about their accomplishments and interests.

Lindberg established a HPCCIT Executive Committee that included not just the big four agencies but also varying participation by smaller, generally applications agencies. That group helped plan HPCCIT Subcommittee meetings and identified larger issues before bringing them to the HPCCIT.

The April 1993 HPCCIT meeting materials included two items that Lindberg had written:

- *What are the Major Achievements of HPCC So Far,* including that "there is one national high performance network project within the Federal government" since there easily could have been four or more.
- *What Have You Learned Through the NCO Experience*: the "excellent, reliable, and self-motivated people from all" HPCC agencies; their "surprising tolerance for the efforts required to adjust common goals to satisfy the numerous agency mission requirements;" and that "OSTP/FCCSET crosscuts are extremely time consuming [and] are worthwhile for projects of clear national importance and cross agency relevance but … are not to be used for less urgent objectives."

Dr. Lindberg announced at the January 1995 HPCCIT meeting that he would step down as NCO director in March. One could hear a pin drop; minutes seemed to pass as those present digested the news. In a January 25 letter, Vice President Al Gore thanked Lindberg for his "dedicated leadership [that] was instrumental in taking HPCC through its formative stages and in making it into the highly successful program which it has been,: and praised the "excellent work which government, industry and academia have produced under the auspices of HPCC to maintain our nation's global leadership in science and engineering." In March 1995, OSTP Director John H. Gibbons hosted a reception in the Old EOB's ceremonial Indian Treaty Room honoring Lindberg's service.

4. 1995-2021: The Next Generation Internet, Health IT R&D, and HPCC Today

The HPC Act of 1991 was first amended by the Next Generation Internet (NGI) Research Act of 1998 [16]. NGI goals (which they met) were experimental networking research, high-performance and ultra-high-performance connectivity testbeds, and revolutionary applications. DOE, NASA, NIST, and NSF had proposed a $100 million/year plus-up for themselves for FY 1998 and FY 1999. Lindberg wanted NLM included, so he added $5 million from NLM's existing budget. Congress rewarded that act by adding $5 million to the NLM budget. That $5 million paid for the development of MedlinePlus.gov.

Lindberg testified at a 2000 NGI hearing [17]. He recalled that in 1996 Senator Bill Frist, a physician and chair of the subcommittee holding the hearing, did the first public MEDLINE search via the Internet. Between then and 2000, those searches had grown from 7 million per year to 250 million per year, with the general public fully a third of those users. He stated that both GenBank and the recently released ClinicalTrials.gov also needed the NGI.

The HPC Act of 1991 was also amended in 2007 and 2017 [18-19]. Changes include officially calling for periodic reviews and strategic plans and calling (again) for Grand Challenges. The amendments also changed the HPCC name; today it is the Networking and IT R&D (NITRD) Program. More than 20 agencies participate. It has expanded the number of components to include, for example, artificial intelligence, robotics, and wireless technologies.

Dr. Howe supported Dr. Lindberg from 1992 through 2015. She transferred from NIST to NLM in 1993, with the unwritten understanding that she could stay at the NCO. She moved with the NCO to NSF space in 1995 and remained until 2007 with titles Chief of Staff, Associate Director, and Acting Director. In the early 2000s she supported Lindberg in his position as a co-chair of the NITRD Health IT R&D (HITRD) Interagency Working Group (IWG), the Program's first and only applications-oriented IWG, in which fifteen agencies now participate. Upon her 2007 return to NLM, she was assigned to an office whose shelves happened to hold old HPCC materials, which she organized. With Lindberg's permission, she successfully asked that the NCO return the NCO library, said yes to more than a dozen cartons labeled NCO/HPCC found in NLM basements (including the medicine and computing articles dated 1936-1994 that Lindberg had moved from his NLM office to his NCO office) and built an archive. While Lindberg's guidance was to "save everything," he seemed chagrined at 48 cartons that measured 59 linear feet, more than the usual for some notable physicians. The archive is officially the NCO/HPCC archive because that is an official Government name. In 2017, Howe completed the archive's public-facing finding aid [20].

Today's NITRD Program (nitrd.gov) still has the same overall structure and the same inclusive and trusting agency relationships that Lindberg had nurtured. Beyond their contributions to medicine and health (including COVID-19 R&D), thirty years of steady HPCC/NITRD R&D have created, enabled, and/or improved climate modeling and weather forecasting; energy sources and energy efficiency; environmental understanding; the Internet and search engines; national defense and intelligence; remote and STEM education and training; space exploration; wireless networking and cell phones; and more. They are all Lindberg's HPCC legacy.

5. HPCC and Telemedicine at NLM

From 1987 when NLM first participated in HPCC activities through his 2015 retirement, Dr. Lindberg was a liaison between the healthcare and HPCC communities. Telemedicine was a key focus area that combined health care and communications, the second C in HPCC.

Lindberg initiated an NLM research contract program to provide examples of how physicians could practice better medicine by using advanced computing and networking capabilities along the "Information Superhighway." Twelve multi-year HPCC Health Care Awards were made in 1994 in four areas: testbed networks to link hospitals, clinics, medical schools, and libraries to allow for sharing of medical data and images; collaborative technology for real-time treatment of patients; information access; and virtual reality for medicine [21]. Many of these awards demonstrated the use of advanced high-speed networks.

NLM sponsored a 1995 study, "Telemedicine: A Guide to Assessing Telecommunications for Health Care", by the Institute of Medicine (IOM) (now part of the National Academies of Science, Engineering, and Medicine) [22]. It documented "the benefits and costs of this blend of medicine and digital technologies" so that "cautious decision-makers" might knowledgably invest in its use and development.

Shortly after Lindberg stepped down as NCO Director and returned to being the full time NLM Director, he recognized that the healthcare and health research communities still needed to play a role in the HPCC Program. His solution was to establish the Office for HPCC (OHPCC) within the Office of the NLM Director. For agencies or activities involved in healthcare or health-related research, whether they were part of the HPCC Program or not, OHPCC became a resource for HPCC information and guidance.

Dr. Lindberg asked Michael Ackerman, Ph.D., to serve as the Assistant Director of NLM for HPCC and as Chief of the new OHPCC office. While OHPCC was organizationally part of LHNCBC, it had a direct connection to Lindberg's office. On one of Lindberg's early visits to OHPCC, Ackerman inquired about Lindberg's vision for HPCC and OHPCC; he needed to draft a position description that reflected Lindberg's expectations. Ackerman sat pen in hand ready to take notes. Lindberg said that notes were not needed: "The job description is very simple. Do good deeds and other duties as assigned." With that, he turned and left.

This anecdote illustrates Dr. Lindberg's relationship with most of the people he hired. He had the ability to find knowledgeable, smart, and creative people whom he could trust. He supported them and gave them great freedom. However, he wanted to be kept informed and was always eager to get involved when needed.

As OHPCC Chief, Ackerman represented NIH in the HPCC Program's Large Scale Networking (LSN) Working Group. This group comprised agency representatives conducting or funding technical research to support the future Internet. While NLM itself didn't conduct or fund such research, Lindberg knew that NLM could provide practical, real-world healthcare testbeds for evaluating advanced networking technologies. Nonetheless, early on, NLM's presence in LSN and HPCC was barely tolerated. That lasted until the Program gave one of its annual in-person presentations for the U.S. Congress. NLM had the last position on the agenda, and during his presentation Ackerman explained how the technologies described by his HPCC colleagues would be used in healthcare. The reaction of the Congressional panel was "Why didn't they just say so?" After that, NLM was always placed towards the beginning of the agenda.

With the IOM Telemedicine Study in hand, NLM next funded demonstrations of advanced telemedicine through its National Telemedicine Initiative. Anticipating projects that might be proposed, Lindberg knew that sending personal health information over the nascent Internet would require security and privacy protection. NLM sponsored a National Research Council (NRC) study to examine "technological and organizational aspects of security management, including basic principles of security; the effectiveness of technologies for user authentication, access control, and encryption; obstacles and incentives in the adoption of new technologies; and mechanisms for training, monitoring, and enforcement." "For the Record: Protecting Electronic Health Information" was published in 1997 [23]. That report included recommendations that ultimately formed the basis for many Health Insurance Portability and Accountability Act (HIPAA) regulations.

In 2004, National Telemedicine Initiative Awards were made for 19 projects. Demonstrating his ability to promote and spotlight NLM projects, Dr. Lindberg invited then-HHS Secretary Donna Shalala to announce the awards. "Telemedicine offers us some of our best and most cost-effective opportunities for improving quality and access to health care. The projects we are supporting will evaluate the use of telemedicine in a wide variety of settings, all the way from the care of newborns and children with disabilities, to the elderly and chronically ill, and those needing a range of specialist care," Secretary Shalala said [24]. "These are imaginative and well-targeted projects that will help us determine how we can best use information via telemedicine for clinical decision-making" [24].

All journals indexed in NLM's MEDLINE are vetted by NLM's Literature Selection Technical Review Committee (LSTRC). At that time, eligible journals had to have their articles independently peer reviewed. Lindberg knew that most telemedicine articles appeared in "grey literature" and therefore couldn't be included in MEDLINE. As part of the National Telemedicine Initiative, NLM supported the Telemedicine Information Exchange (TIE) both to support the telemedicine community and to experiment with "grey literature" citations [25]. Many of the publications cited by TIE were later included in MEDLINE.

The additional funding provided when the NGI Research Act became law in 1998 gave Lindberg the means to encourage the healthcare community to experiment with futuristic possibilities for patient care. Lindberg and Ackerman gave many presentations in anticipation of NLM's next funding opportunity. "If we are to benefit from the fruits of modern medical science we must be able to transfer massive amounts of data — instantaneously, accurately, and securely," said Lindberg [26]. NLM's goal was to demonstrate how the NGI could "affect health care, health education, and health research systems in such areas as cost, quality, usability, efficacy, and security." It was clear that Lindberg's vision was way beyond the imagination of the health community, so NLM's NGI initiative was divided into two phases. Phase I invited short proposals to explore the possibility and feasibility of using NGI technologies to provide healthcare in ways that were then not possible, and helped raise healthcare community awareness. Phase II invited proposals for implementing and testing the kinds of ideas generated by Phase I. Twenty-four Phase 1 awards were made in 1998 and fifteen Phase 2 awards were made in FY 2000 [27-28]. The funded projects were designed around NGI capabilities expected to become available in the not-too-distant future: virtually error-free service; security and medical data privacy; "nomadic" computing; network management; and infrastructure technology for "collaboratories." Twenty years later, these qualities are part of everyday networks.

The Internet was evolving rapidly then, and so was NLM's view of healthcare's Internet future. The NLM Scalable Information Infrastructure (SII) program was established in FY 2003 as a continuation of Phases I and II of the NLM NGI program. SII supported the research priorities in the President's Information Technology Advisory Committee's (PITAC) 1998 report "Information Technology Research: Investing in Our Future" [29]. (PITAC was the Presidential advisory committee called for in the HPC Act.) The SII program's purpose was "to encourage the development of health-related applications of scalable, network aware, wireless, geographic information systems, and identification technologies in a networked environment." SII focused "on situations that require, or will greatly benefit from the application of these technologies in health care, medical decision-making, public health, large-scale health emergencies, health education, and biomedical, clinical, and health services research." Projects had to use networks "linking one or more of the following: hospitals, clinics, health practitioners' offices, patients' homes, health professional schools, medical libraries, universities, medical research centers, laboratories, or public health authorities." Eleven awards were made [30].

Over the 15 years since NLM's HPCC telemedicine programs ended, many of their demonstration projects and the methods derived from them were further developed. Since the spring of 2020 the world has been dealing with the COVID-19 pandemic, and in doing so has depended heavily on the Internet, now thought of as broadband networks, and on telemedicine. Thanks to those decades of R&D, telemedicine technologies were readily available, and they were widely used for both routine healthcare and care unique to the pandemic. Dr. Lindberg was correct, "Do good deeds."

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The Visible Human Project

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Abstract. This paper gives a flavor of Dr. Donald A.B. Lindberg's view of the expanding role of libraries, his curiosity, and his tolerance for taking educated risks, through the creation and nurturing of National Library of Medicine's Visible Human Project. That project produced the Visible Man and Visible Woman datasets and a suite of tools for presenting and analyzing those and similar datasets. The results are used in teaching anatomy and other medical school courses and in software from the open-source Insight Tool Kit (ITK) that is included in many if not most volume-reconstructing systems. This story is a bit personal. From the beginning we recognized and understood each other since we were both "boys from Brooklyn".

Keywords. Donald A.B. Lindberg, U.S. National Library of Medicine, Visible Human Project, Insight Tool Kit.

Donald A.B. Lindberg M.D.'s vision for the future, his love of scientific adventure, and his leadership skills made the Visible Human Project possible. I had joined the U.S. National Library of Medicine (NLM) early in 1987 as the Chief of the Educational Technology Branch in the Lister Hill National Center for Biomedical Communication (LHNCBC). My assignment was to demonstrate to American medical schools that microcomputers could and should be used as teaching tools within their curricula. It was the era of the IBM Personal Computer AT and video discs. A video disc player could be interfaced to and controlled by the microcomputer. The microcomputer could present the curriculum content and command the videodisc system to present an appropriate image or video. NLM had developed a video disc of pathological images, Dr. Lindberg's medical specialty, suitable for use in medical school curricula.

As part of my job, I traveled to several medical schools to give seminars on microcomputer-based education and the assistance that NLM was prepared to provide. In the fall of 1987, I made such a presentation at the University of Washington in Seattle. After the talk, Cornelius Rosse M.D., the Chairman of the Biological Structure Department, told me that if interactive microcomputer-based education is to be used in medical school, it should be used in the teaching of Anatomy. He explained that a student gets to see a particular anatomical site only once, since it is later dissected. The student cannot go back and review. Also, anatomy is three dimensional yet the student gets to see it only from one direction. One cannot really "study" anatomy like one studies other subjects. But image-based interactive computer programs would allow a student to re-experience a cadaver's dissection, to review it, and to "study".

That conversation made me think. Would focusing on anatomy provide the example that would get medical schools to adopt interactive technologies? When I returned to NLM, I went to see Harold M. Schoolman M.D., NLM's Deputy Director for Research and Education. Dr. Schoolman told me that Dr. Lindberg had commissioned a Long

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Range Plan shortly after he became NLM Director in 1984. He explained that if I wanted to interest Dr. Lindberg in such an adventure, I would first have to show how my idea could support what had in January 1987 become the NLM Long Range Plan, particularly the underlying documents supporting recommendation 5.3.2, which says that "NLM should thoroughly and systematically investigate the technical requirements for and feasibility of instituting a biomedical images library" [1-2].

With this advice in hand, I visited Daniel Masys M.D., the LHNCBC Director. He suggested that we organize and hold a workshop to explore what a three-dimensional digital data set of human cadaver anatomy images might be used for, particularly by an Anatomy Department. We did just that, and the workshop's recommendations appeared as an LHNCBC Technical Report in the fall of 1988 [3].

I was almost ready to visit Dr. Lindberg, but I first discussed my ideas with various colleagues. The majority thought that it was a bit crazy. But not Dr. Lindberg. He listened, seemed interested, asked questions, and assigned some homework. He seemed intrigued and left me feeling encouraged. I was thrilled that the answer wasn't no!

In the spring of 1989, Dr. Lindberg and I attended an International Medical Informatics Association (IMIA) International Symposium on Medical Informatics and Education held on the campus of the University of Victoria in Victoria, Canada. School buses provided transportation to the conference dinner, which was held some distance from the symposium location. I took a seat on the bus, and Dr. Lindberg took another in the row in front of me. During our journey to dinner, he turned around and asked me a question: If he were to allow my proposed anatomical imaging project to proceed, would I take the leadership role? Without hesitation I said yes, and without hesitation he said that we would do it. Then he asked what the project should be called. I said the Visible Man. He asked what about a woman. I could have said if we use a female cadaver we will call it the Visible Woman, but I quickly decided to see if this might be an opportunity and said that we can call it the Visible Couple, implying two cadavers. He thought for a moment and said, "Let's call it the Visible Human", the same name for one or two cadavers. The answer to doing two cadavers wasn't no!

Soon it was time to submit proposals for NLM's annual budget process. I prepared and submitted a budget proposal and justification for the Visible Human Project assuming two cadavers, one male and one female. This was the first time I actively participated in the NLM annual budget process so I was not alarmed when I didn't receive any feedback for my proposal. When the budget was announced, it contained a budget line for the Visible Human Project. The approved budget was what I had proposed for the first of three years. I called Dr. Lindberg to thank him and promised to immediately start the contracting process. He said stop. The money was not to begin doing the project, but rather the money was to pay the costs of an NLM Board of Regents (BoR) Special Committee to decide if the project should be done. "But you said that we were going to do the project," I questioned. "We will," he responded, "but after it is approved by the Board of Regents." "What if they don't agree?" I protested. "They will approve the project," he said with confidence. "That's my job." What I had experienced was an example of Dr. Lindberg's gift of knowing when and how to take educated risks.

With the go ahead from the NLM BoR, Dr. Lindberg assembled an NLM Board of Regents Long Range Planning Panel on Electronic Imaging. The panel was made up of 24 people, each representing an area of medicine, computer science, or entertainment in which images were of prime concern. The panel held three formal meetings over a nine-month period, at the end of which they issued a report, Electronic Imaging: Report of the Board of Regents, which not only approved the project but also suggested a budget, the

steps necessary to successfully execute the project, and follow-on projects [4]. It was a blueprint for managing the Visible Human Project. And, as he had promised, the new fiscal year budget contained a funded budget line to implement the Visible Human Project.

The Visible Human Project would include separate collections of images from a male and a female cadaver. There would be CT serial cross-sectional images, MRI serial cross-sectional images, and anatomical serial cross-sectional images, each from head to toe. The Request for Proposals stipulated that the serial cross-sectional images in all three modes had to correspond with each other: Each CT cross-sectional image had to correspond with a specific MRI cross-sectional image, which had to correspond with a specific anatomical cross-sectional image. The driving principle was that while clinicians can review radiological images, they have to treat the patient's anatomy. A computer program could overlay related images so the student could learn to recognize anatomy through the corresponding radiological images.

The dataset of the digitized images was estimated to be about 15 gigabytes in size. In 1990, a digital dataset of that size was almost unthinkable. The largest portable data storage medium at the time was the CD ROM, which holds about 0.7 gigabytes of data. The NLM BoR Planning Panel on Electronic Imaging discussed the dataset distribution problem and agreed that there would eventually be a solution. Dr. Lindberg never showed any hesitancy related to this issue.

The Visible Human Project Request for Proposals was advertised, bids were received, questions were asked of the bidders, answers were received, and a decision was made. The contract was sent to Dr. Lindberg's Office for his signature. He wanted to see me. "How was this decision made?" he asked. I started to explain the process. He stopped me. "I want a written report that documents the process, lists the expert panel members, and presents their justification for choosing the successful bidder." I could tell from Dr. Lindberg's tone that it would do no good to protest or explain. It took over a week to put together the report. I was called to his office a few days after I submitted it. He had the contract with him. He signed it, gave it to me, and wished me luck. I didn't ask any questions. I thanked him and left.

I really never thought about the incident until about 20 years later. Dr. Lindberg and I were at a professional meeting dinner where he approached me and apologized for the very hard time he gave me over the contract for the Visible Human Project. Before I could say anything, he explained: "One of the bidders was from outside the United States. If that bidder were given the award and then something went wrong, there would at least be a chance of successfully explaining it to Congress. But the award was made to an institution in Denver, Colorado, the heartland of the United States. Your procedures and justification were so good that there was no way to disqualify your recommendation. But now that the project is such a great success, I need to apologize. You made the right decision." I was speechless, and at that point learned a lesson in what taking educated risk was all about.

It was the job of David Whitlock M.D. and Victor Spitzer Ph.D. of the University of Colorado Denver, the principal investigators of the winning contract proposal, to find appropriate cadavers from which to create the anatomical cross-sectional images specified in the contract. Two years went by with no luck. Then Dr. Spitzer called me with a question. Some of the prisoners on death row in Texas had willed their bodies to science, and the Project was offered the cadavers. I decided that this was a question for Dr. Lindberg, and he in turn called for a special NLM Senior Staff meeting. The question at hand was more than a one of legality and ethics; it was also a question of optics. The

history of the modern study of anatomy began with robbing the graves of murderers for their cadavers. Were we not repeating history? Dr. Lindberg led the discussion. All present agreed that they knew of no federal law or rule that prohibited accepting the offer. For example, HIPAA rules presented no issues because the deceased have no HIPAA protection. On personal ethics, no one present voiced an objection. But the optics were of concern. After some discussion, Dr. Lindberg suggested a solution: Accept the donations, but be totally transparent about the nature of the donations in any announcements that would be made when the datasets were made publicly available. NLM would hold back only the names of the deceased. The argument was that if NLM were not totally transparent, the press might fill in the blanks with misinformation that might cause more problems than the truth. There is historical justification for this approach in that there is a tradition in medicine of never revealing the identity of a volunteer subject. We agreed that NLM would never reveal the name of the subjects.

Several months went by before Texas sent a very fresh cadaver to Denver. I was notified early in the morning that the cadaver had arrived and that our CT and MRI scan protocols had begun. By noon, less than 12 hours after the death, I was told that the cadaver was unexpectedly showing signs of decomposition. By 3:00 pm I was informed that the cadaver rapidly decomposed to the point that it was useless and it would be disposed of. What happened?

It took some time to discover that potassium had been a component of the lethal injection. Its purpose was to stop the heart. But potassium has another effect. It causes the breakdown of cell membranes that in turn causes a general decomposition of the body. I always kept Dr. Lindberg and NLM Senior Staff informed about this project at their regular meetings. I told this story at the very next meeting. Dr. Lindberg immediately slammed his hand down on table and cried out, "Oh no, he was right." There was an immediate silence in the room. I was stunned. I said, "I'm sorry, but did I say something wrong?" I'm an engineer, not a physician, and sometimes I get my technical medical terms mixed up. "No", he said. "I just remembered. When I was a pathology resident, the old man in the pathology morgue told us that if a cadaver ever arrives with a high serum potassium level, do what you need to do as soon and as fast as possible because they are nothing but trouble. The old man was right." So, I asked Dr. Lindberg, "We are here in the National Library of Medicine with the world's medical literature. Where is this written?" Dr. Lindberg answered, "It isn't. But the old man knew!"

From that point on, the Project moved ahead with few dramatic surprises, but it certainly benefited from technological advances. Digital image capture technologies had become easier and better by then. The budget for the Project allowed for anatomical images to be captured on film, which would be digitized later. In addition, digital cameras had by then become reliable enough and capable of enough resolution that we wanted to add a digital camera so we could capture the digital images directly. Those cameras were still very expensive, but Dr. Lindberg supported the budget addition that let the Project also use a digital camera.

Drs. Spitzer and Whitlock learned many lessons while collecting the serial cross-sectional images of the male cadaver. As they were sectioning and imaging the male cadaver every 1.00 mm, they were realizing that they could in fact capture serial digital images every 0.33 mm. Three times the number of images of course meant three times the work and three times the cost. In this and in every other case, Dr. Lindberg enthusiastically supported the proposed improvements and increased the Project's budget, which slowly doubled, from $700,000 to $1,400,000. Dr. Lindberg never complained and never viewed these increases as cost overruns. They were improvements to the end

product that took advantage of the latest in digital technologies, technologies that were not available when the Project was envisioned or awarded.

It also meant the dataset would be about three times the size, 40 gigabytes. It was now 1994. The speed of the national Internet had increased to the point that transferring a dataset of this size was almost practical. The original distribution problem was solved.

The availability of the male Visible Human Dataset was announced at the Annual Meeting of the Radiological Society of North America (RSNA) in Chicago in November 1994. Dr. Lindberg joined Drs. Spitzer and Whitlock and me for the announcement. He proclaimed his support and gave full credit to the people who had created and guided the project and successfully carried out the work. A year later, with Dr. Lindberg present in the same venue and in the same way, the availability of the female Visible Human Dataset was announced.

By January 1998, I had been working with Dr. Lindberg at NLM for ten years. When Dr. Lindberg decided that a presentation on the successful Visible Human Project should be on the agenda for the next NLM Board of Regents, I had the opportunity to try out my version of Dr. Lindberg's use of educated risk. He wanted part of the presentation to be a demonstration of an application that used a Visible Human dataset. I knew whom to invite. Dr. Lindberg asked if I would guarantee that the demonstration would work. "Of course it will", I answered affirmatively and enthusiastically. I invited Gregory Merril, the CEO of HT Medical, to present his company's Virtual Bronchoscopy System. The presentation and demonstration were scheduled for just after the morning coffee break. When I arrived at NLM that morning, I had an idea. Mr. Merril was setting up the demonstration. I asked him if he could guide someone else who would do the actually demonstration. He said that he could and asked who I had in mind. "Dr. Michael DeBakey," I answered. During the coffee break I asked Michael DeBakey M.D. if he had ever done a bronchoscopy. He said he had done them many times, so I invited him to do the virtual bronchoscopy demonstration. He was delighted.

Then I realized that I had not yet told Dr. Lindberg. "You are sure that this is going to work?" was his tentative response. "I guaranteed it to you," I again enthusiastically responded. I could hear in his voice that he was not fully convinced, but he decided to let me go through with it. Dr. DeBakey performed the bronchoscopy flawlessly, and the virtual system performed flawlessly too. The demonstration was set up in a way that Dr. DeBakey's view through the bronchoscope was projected on a big screen so that everyone in the room could see it. According to the minutes of the meeting, "Dr. DeBakey described what he was "seeing" in the lungs and, when he was finished, he said that what he and we had seen was, in fact, very real" [5]. At the next break Dr. Lindberg told me that he never had any doubts.

The Visible Human Project was a complete success. It was used in high school, college, and medical school teaching; imaging algorithm development, testing, and comparison; physiological and radiation modeling; art; and digital network testing. It took about two years before we heard any criticism from the anatomical teaching community, our primary target. They reminded us that they taught anatomy by organ, not by cross-section. They suggested that we take the Visible Human serial cross-sections and reconstruct each of the body's organs from them. In order to do that, a map of each cross-section would have to be created showing to which organ each dot in the cross-section belonged—what's known as segmentation. Then the dots belonging to the organ of interest from each cross-section would have to be put back together - registration. This was then a manual process and was very time-consuming and very expensive. A few companies were doing it as part of developing their educational products. The integrated

products were available, but the underlying segmentation and registration components were not. I realized that the next scientific challenge was to develop the algorithms that could automate the segmentation and registration processes.

Doing the segmentation and registration on Visible Human data would create the organ models only from the Visible Human datasets. Developing segmentation and registration algorithms would allow the anatomy community to have the organ models that they wanted based on the Visible Human datasets. It would also allow organ models to be created from any future Visible Human dataset, from NLM or elsewhere. Outside the anatomy community, it would, for example, allow the radiology community to reconstruct organs of interest from their serial CT and MRI images. Radiologists would no longer have to envision their serial images in three dimensions, making their work easier. Viewing and interpreting images with both non-radiology colleagues and patients would also become easier.

With this idea, with the target audience identified, and with estimates of how long it would take to accomplish and how much it would cost to complete, I asked for a special meeting with Dr. Lindberg. He listened, asked some questions and then said, "I guess the inexpensive part of the Visible Human Project is now over." The cost for creating the Visible Human datasets was $1.4 million. My estimate of the cost of this new project was $7.5 million.

A group of experts was formed to create these algorithms. NLM hosted their first meeting, to which Dr. Lindberg was invited. During the first coffee break, he informed me that I had a problem. "There must be more than a token woman who is knowledgeable in this area. Why are they not here?" Dr. Lindberg was always sensitive to representation and opportunity, of which this is just one example. I took the hint. And as was Dr. Lindberg's habit, he checked on my progress. I was happy to let him know that I had identified and recruited additional qualified women.

A little more than three years later, in 2002, the open-source Insight Tool Kit, ITK, was released [6]. It included segmentation and registration algorithms, and the anatomy community immediately found it useful. As predicted, ITK algorithms for three-dimensional reconstruction were soon included in radiological workstations, first by GE and Siemens and later by others. But it was also used by pathologists for volume reconstruction of serial pathology sections, by astronomers for volume reconstruction of their serial sections of the heavens, and by many other disciplines that were studying serial images from things that were size-wise in between.

In 2009, Dr. Lindberg and I planned one more major Visible Human-related project together. The question "Will NLM produce additional Visible Human datasets?" was asked at every Visible Human presentation. Additional datasets would represent the variability of human anatomy. We now had the means for segmentation and registration of any volume of interest in the Visible Human datasets. Why not create software that would allow the user to modify each volume of interest within realistic boundaries in order to build their own three-dimensional digital cadaver? The software would require a database containing the normal range of dimensions for each volume of interest in the body, i.e., organ, muscle, gland, blood vessel, bone, cartilage, etc. Dr. Lindberg suggested that we should first do the bones as they were the only body component whose size was constant, i.e., did not change when touched or with motion. I did some preliminary research, creating a digital folder filled with two gigabytes of papers from the anatomical variance literature, and then put together a proposal. By then the politics of agency funding had changed. Instead of a discussion on how the project would be

funded, I was faced with Dr. Lindberg's question, "So what are you not going to do." I could see his uneasiness and frustration, but that was the reality of the time.

Each of the previous parts of the Visible Human Project could be characterized as high risk, high payoff when completed, with a reasonable chance for success. The same was true for the current proposal. Dr. Lindberg and I often realized that there were projects for which only the government could afford the risk. The budget and national policy could no longer support taking such risks in this domain.

NLM's continuing research funding under the Visible Human Project banner came to an end. My career had become defined by that project. Dr. Lindberg, whenever he mentioned the Visible Human Project in a talk, proudly said, "I gave him permission to take some time and do the project, and he hasn't had time to do anything else since." That's what two boys from Brooklyn were able to accomplish.

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Section Two

The Multiple Dimensions of Expanded Access to Health Information:
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The Multiple Dimensions of Expanded Access to Health Information: Don Lindberg and the U.S. National Library of Medicine

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Abstract. When Donald A. B. Lindberg M.D. became Director of the U.S. National Library of Medicine in 1984, trained searchers, primarily librarians, conducted less than three million searches of NLM databases. They paid for their fair share of the commercial telecommunications costs to reach NLM's computer system. In 2015 when Lindberg retired, millions of scientists, health professionals, patients, members of the public, and librarians conducted billions of free searches of NLM's greatly expanded electronic resources via the Internet. Lindberg came to NLM intending to expand access to biomedical and health information along multiple dimensions: reaching more users, providing more types and volumes of information and data; and improving the conceptual, technical, and organizational connections needed to provide information to users when and where it is needed. By any measure he and NLM were spectacularly successful. This chapter discusses some key decisions and developments that contributed to that success.

Keywords. Donald A.B. Lindberg M.D., U.S. National Library of Medicine, MEDLINE, Internet Access, Consumer Health Information, History, Librarians

1. Introduction

Donald A.B. Lindberg M.D. became Director of the U.S National Library of Medicine (NLM) in August 1984. In that fiscal year, trained searchers, primarily librarians, at 2,461 U.S. institutions conducted 2.8 million searches of bibliographic, thesaurus, chemical, toxicological, and cancer information databases on NLM's computer system, an 11 percent increase from the previous year. All indexing and cataloging data available online at NLM were keyed de novo for the Library's databases. Some of the data in the factual databases were received on magnetic tape from other federal agencies and organizations. Online users paid fees to cover their proportional share of the cost of the commercial value-added telecommunications networks used to reach NLM's computer system. NLM licensed MEDLINE, its premier database of indexed citations and abstracts, to other U.S. online database providers and had formal agreements with the Pan American Health Organization and the governments of 13 countries to facilitate access outside the U.S. Some international partners received copies of the databases on magnetic tape and mounted them locally using their own software or copies of NLM's ELHILL retrieval software; others managed online access to NLM's system in Bethesda

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MD for users in their countries. By 1984 standards, NLM's databases were widely accessible and very heavily used.

By the time Lindberg retired in March 2015, millions of scientists, health professionals, patients, members of the public, and librarians worldwide conducted billions of free searches of NLM electronic resources via the Internet each year. The amount of information and data NLM organized and disseminated electronically was enormous, including richly linked bibliographic, molecular biology, genetic, genomic, biochemical, chemical, toxicological, environmental, and clinical trials data; born-digital and digitized full text; still, moving, and high resolution born-digital images; scientific and health data standards; informatics tools for system developers; and health information for the public. Thousands of individuals and organizations submitted data for inclusion in NLM's electronic resources. Users searched or downloaded information directly from an NLM Web site, found it via an Internet search engine, or used an "app" that provided value-added access to NLM data. Thousands of commercial and non-profit system developers and scientists regularly used NLM applications programming interfaces (APIs) or download sites to obtain data for their systems, products, and research.

Important prerequisites for this massive expansion in access to biomedical information were in place when Lindberg arrived at NLM. They included a mission broad enough to encompass great expansion, i.e.,"…to assist the advancement of medical and related sciences and to aid the dissemination and exchange of scientific and other information important to the progress of medicine and to the public health;" a multidisciplinary staff with a wide range of relevant expertise and experience; existing highly regarded information services on which to build; and a U.S. nationwide network of health sciences libraries actively engaged in facilitating access to biomedical information for health professionals and researchers in academic institutions and hospitals [1-2]. Lindberg fully appreciated these assets. In combination with his expectations about advances in computing and communications and in biomedical science, they were the reasons he came to NLM.

Lindberg saw a golden opportunity for NLM to make a positive difference. "What seems needed now is to adapt these general and useful technologies to the specific jobs of biomedicine. Progress might eventually come in any case, but a concerted effort on the part of the National Library of Medicine could speed this up" [3]. For many "specific jobs of biomedicine" there was "an urgent need for improved access by health care professionals and scientists to the fast-growing scientific literature of newly discovered biomedical concepts, treatments, and preventatives - across wide range of practical and theoretical problems" [3]. Helping to meet this need was NLM's mission.

As Lindberg knew well, expanding access to biomedical and health information is a multidimensional – and multidisciplinary - undertaking with no endpoint. The definitions of easy, reliable, and useful are moving targets, affected by changes in available technologies and services and in user expectations [4]. Progress requires work to expand and engage the universe of active users, to increase and enhance the information and data available, and to facilitate effective connections between the two. Technical connections, e.g., a web capable device and Internet access, are essential, but insufficient. Users must be aware of relevant information and data sources, understand their utility, and have an opportunity to provide feedback on the interfaces to them. Intra-organizational arrangements, inter-organizational relationships, and public policies must promote rather than restrict access to biomedical information and data. Highly trained and motivated

people are needed to build, maintain, and manage reliable systems that "understand" users and connect them to the right information at the right time and place.

Under Lindberg's leadership, NLM worked with many others to expand access to biomedical information in all these dimensions.

2. Initial Steps Toward Expanded Access

Lindberg had six priorities when he came to NLM in 1984, all relevant to expanding access to biomedical information [5].

- Increase public and Congressional awareness of NLM and its services.
- Develop a long range plan based on extensive input from NLM users and stakeholders.
- Provide a user-friendly interface to MEDLINE for health professionals [6].
- Initiate the Unified Medical Language System (UMLS) project [7].
- Increase support for biomedical informatics training and research and development of Integrated Academic Information Management Systems (IAIMS) [8-10].
- Improve relationships between NLM and publishers and the commercial information industry [11].

The NLM Board of Regents initiated action on public awareness and long range planning at their October 1984 meeting, the first held after Lindberg's arrival [12]. He and the Board considered both critical to garnering the resources needed for NLM to help health care and biomedical research "… benefit from the dazzling technological discoveries that are available to us now from computer and information science, telecommunications engineering, physics and chemistry" [3]. The positive effects of increased public awareness and advocacy for the compelling recommendations arising from the planning process are described in chapters throughout the book [e.g., 12-14]. An early spectacular result was the establishment of the National Center for Biotechnology Information (NCBI) at NLM in 1988, which had profound effects on expanded access in all its dimensions [12]. As just one example, NCBI's positioning within NLM speeded the creation of robust links between published biomedical literature and multiple levels of biological, chemical, and clinical research data.

Lindberg also moved quickly on the more specific priorities on his initial list [6-11]. Congress added additional funds to the NLM budget for two of them, UMLS and IAIMS, before the initial NLM Long Range Plan was issued in 1987.

Characteristically, Lindberg did not allow attention to major initiatives to get in the way of his desire to know more about NLM's operations and services and to identify opportunities for immediate improvements in access. A good day for Don Lindberg was a day he learned something new. He was pleased and not surprised to find much to admire, e.g., NLM's new online cataloging and indexing systems, and happy when no intervention from him was necessary. He was interested in learning about positive endeavors he could help to advance, as well as any matters ripe for review and change [e.g., 15, 11].

Shortly after his arrival, in response to a request from a key member of NLM's nationwide library network, Lindberg engineered a quick substantive improvement in access. Allison Bunting M.L.S, then Director of the Regional Medical Library at UCLA, "…asked him if it would be possible to change NLM's practice of the nightly

maintenance shutdown of the NLM computers…it was right in the middle of Hawaii's workday and the librarians in HI were having to come in at 3 am to get their searching done. He readily agreed saying that the least he could do was provide equal access to our 50th state ...″ comparable to what was available to online users in Europe [16]. Based on his experience with IBM systems, Lindberg knew there was a way to keep the online system up during a period of low use while accomplishing the system maintenance in parallel. He gave the NLM Office of Computer and Communications Systems the assignment to gradually reduce the downtime. Less than a year after his arrival, NLM's online system was available 24 X 7 [17].

It was the definition of folly to answer Lindberg's technical questions with vague generalities about what could or could not be done. He was, however, an ideal leader for an organization with a large computing and communications operation during a period of immense technical change and explosive growth in use. Lindberg knew access to NLM's resources had to be fast and uninterrupted in the face of constantly escalating use and growing computer security threats. His concurrent appointment as first Director of the National Coordinating Office for High Performance Computing and Communications (HPCC) gave him even greater incentive and opportunity to apply the latest technological developments and security measures to NLM's systems and services [18].

Lindberg arranged for an initial "white hat" penetration test of NLM's production and research computing systems in 1995 before this became common. He readily approved investments necessary to keep NLM at the forefront of high speed communications; to implement the use of biometrics to authorize entry to the computer center (2002); to establish a second offsite hot back-up computing center to insure uninterrupted access to NLM, U.S. National Institutes of Health (NIH), and U.S. Department of Health and Human Services (HHS) systems (2006); to reduce energy consumption in the computer centers; and to be an early tester and adopter of version 6 of the Internet protocol (IPv6) (beginning in 2011). Under the direction of Simon Liu Ph.D. (2000-2010) and Ivor D'Souza M.S. (2010-present), NLM has been a leader in these areas within the Federal government with major positive effects on fast and reliable access to information and data.

Cost is a barrier to access. To put it mildly, Lindberg disliked the necessity of charging users to recover their fair share of the value-added telecommunications costs needed to access NLM's online services. Given the history of this requirement, with intense scrutiny by the Executive Branch and the Congress, and the large real bill for the commercial networks, there was no quick way to change it [19]. However, Lindberg was able to prevent the expansion of charging for access to some new services. Within months of his arrival, he decided not to charge network libraries for using the new DOCLINE automated document request and routing system. This decision hastened broad adoption of a system that decreased effort across the library network, including at NLM, and increased the speed of document delivery to health professionals and scientists.

3. Direct Access to MEDLINE by Health Professionals

Lindberg arrived at NLM with a strong desire to make the Library's services more directly useful in health care. Although his interest encompassed NLM's toxicological and chemical databases, his immediate goal was to provide an inexpensive mechanism for direct MEDLINE searching by health professionals using the personal computers

increasingly available in their offices and homes. This was a logical first step because the content of MEDLINE was useful to health professionals in its current format.

Dorsch, Faughnan, and Humphreys describe the rapid development and deployment of Grateful Med, an inexpensive PC interface to NLM's ELHILL retrieval system with a memorable name [6]. Its release in February 1986, just 15 months after Lindberg initiated its development, was a major early event in the yearlong celebration of NLM's 150th anniversary. Grateful Med was the subject of an active publicity and marketing campaign and intensive outreach to health professionals by librarians in the nationwide library network. Grateful Med was the principal cause of the dramatic increase in individual health professionals, researchers, and students using NLM's online system. From less than a thousand in 1985, the number rose to more than 100,000 by 1996. Success in expanding access throughout the U.S. encouraged the Congress to increase NLM funding.

Dorsch et al. place Grateful Med in the context of other efforts to increase health professional use of MEDLINE and assess the impact of its short life. Grateful Med's run ended in 1997 when MEDLINE became free to anyone with an Internet connection and a Web browser. Their chapter is the first of several to mention the initial negative response by some librarians, principally in hospitals, to Grateful Med and NLM's unprecedented direct marketing to health professionals and administrators [6,19-21]. Other librarians embraced the role of reaching out and teaching health professionals about Grateful Med. Their experiences informed subsequent expanded outreach efforts by the National Network of Libraries of Medicine [22].

4. Free MEDLINE Access Worldwide

As stated previously, Lindberg did not like charging for online access, and he took steps toward providing free service as opportunities arose. In 1991, he approved NCBI's distribution of the MEDLINE citations in which DNA and protein sequences were published along with the sequence data in a CD-ROM product. This evolved into access via the Internet shortly after the arrival of the first Web browser in 1994, setting the stage for NCBI's Entrez system to replace NLM's ELHILL retrieval system a few years later. Also in 1994, an increase in NLM's AIDS funding allowed Lindberg to respond positively to a request from the HIV/AIDS affected community and make the AIDS databases free [23]. This prompted an immediate increase in use.

Making all of MEDLINE free was a more complicated proposition. Current and potential searchers had to obtain Internet connections so the use of commercial telecommunications networks would no longer be necessary. At Lindberg's direction, NLM and the National Network supported initial connections for many hospitals and their libraries. Beyond this prerequisite, NLM's inflexible legacy retrieval system had to be replaced, a World Wide Web interface implemented, and the political issues associated with eliminating charges navigated very carefully.

Kent A. Smith, Lindberg's Deputy Director during the first 20 years of his tenure, provides a quintessential insider's view of the 13-year path leading from Lindberg's arrival at NLM in 1984 to Vice President Gore's first free search of MEDLINE via the Internet in 1997 [19]. Touching on many developments addressed from different perspectives in chapters throughout the book, he explains how the combination of Lindberg's vision and leadership, advances in technology, astute attention to policy

issues, and help from political supporters and influential advocates led to free access to MEDLINE worldwide in 1997 - and no attempts to undo it.

Many chapters in this book reveal aspects of the tremendous worldwide impact of free access to MEDLINE via PubMed. There were huge increases in the numbers of users and the amount of use. The evidence that a substantial percentage of users were patients and members of the public led to Lindberg's decision to develop new services designed for them, as discussed below. The removal of the cost barrier was key to expanding MEDLINE access to disadvantaged communities and groups in the U.S. and to developing countries [14]. Unfettered access to MEDLINE via PubMed with rich links to full-text and related data had significant positive effects on biomedical informatics research and development [24].

In 1997 few electronic journal articles were freely available on the Web, a fact highlighted by PubMed's links from free MEDLINE citations to articles behind "pay walls" on publishers' websites. Free MEDLINE via PubMed was one of the factors that led Harold Varmus, M.D., then NIH Director, to give NCBI an assignment to build a free archive of full-text biomedical journal articles. This resulted in the release of PubMed Central in February 2000. In turn, the existence of PubMed Central influenced both an increase in the number of free articles available from publishers and the establishment of the mandatory NIH public access policy, effective in 2008 [4]. PubMed Central and the NIH public access policy encouraged the implementation of similar policies by many other biomedical research funders. The net result has been free worldwide access to millions of articles reporting the results of research related to biomedicine and health.

5. Health Information for the Public

During the development of the NLM Long Range Plan, Lindberg the Board of Regents, and some planning panel members seriously considered whether the NLM should expand its services to encompass health information for the public. At that time, they concluded NLM had neither the budget nor an effective delivery mechanism to provide useful services to the public.

In 1997, the public's use of free MEDLINE via PubMed demonstrated the viability of the Internet and Web browsers as a delivery mechanism. Congress also was pursuing the doubling of NIH's budget from 1998 to 2003. In Lindberg's view, an increase of that size required NLM to develop new programs, as well as expand existing ones. Web-based health information services specially designed for the public was a compelling choice.

MedlinePlus, NLM's major information service for patients and the public, was first released with 22 health topics in October 1998. Coincidentally, this was a month after Varmus assigned NLM the responsibility to develop a clinical trials registry, i.e., ClinicalTrials.gov, to meet a legislative requirement for a service enabling patients and their caregivers to find information about trials of drugs for serious conditions [11,25]. Responding to these initiatives, the NLM Board of Regents approved a new policy for NLM information services for the public in 1999. The NLM Long Range Plan, 2000-2005, identified health information for the public as a high priority.

Backus and Lacroix chronicle the development and evolution of MedlinePlus, now used by hundreds of millions of people annually [26]. They discuss Lindberg's influence on key features, including links to other NLM services, e.g., PubMed, Clinical Trials.gov, and the inclusion of multimedia content. Backus and Lacroix also explain how

MedlinePlus and other services for the public were shaped by research and user evaluations, with examples of features and services that were added and retired as warranted by changes in technology and the emergence of better alternatives.

Along with MedlinePlus en espanol, which debuted in 2002, MedlinePlus has been a critical component of NLM and library network efforts to expand public access to high quality health information [14,22]. Just as many subject specific NLM bibliographic databases, e.g., AIDSLINE, BIOETHICSLINE, were merged into PubMed to reduce duplication and make their unique content available where users gravitate, some specialized NLM services for the public, including a directory of resources in multiple non-English languages and Genetics Home Reference, have been merged into MedlinePlus [27].

The MedlinePlus Connect feature employs the UMLS and standard clinical terminologies and code sets to support links between electronic health records (EHRs) and MedlinePlus information about health conditions, tests, drugs, and procedures. The existence of MedlinePlus Connect influenced the requirement for electronic connections to patient education materials in U.S. regulations for "meaningful use" of EHRs. As a result, many users of patient portals and EHRs have ready access to high quality health information provided by NLM.

6. Expanded Access to the History of Medicine and Science

Lindberg had broad interests in the humanities, including a special enthusiasm for history. He quickly identified NLM's history of medicine program as an area where his personal involvement could make a positive difference. Parascandola describes Lindberg's significant contributions to documentation of the history of 20th century developments in science, medicine, and health policy; the digitization of NLM's pre-1963 indexes, historical books, manuscripts, and images; and the expansion of NLM's exhibition program as an outreach mechanism [15].

Lindberg's stature and personal contacts were critical to obtaining important 20th century manuscript materials and participation in conferences and other efforts to document the history of important programs and relatively young scientific fields. Examples include the papers of winners of the Nobel prize in physiology or medicine, the history of the Regional Medical Programs, and the development of the fields of medical informatics and health services research.

The spread of the Internet and the multimedia capabilities of the World Wide Web were particularly valuable for increasing access to the contents of richly illustrated rare books, unpublished manuscript materials and data, and NLM's large collections of historical pictures and films. As described by Parascandola, Lindberg encouraged NLM's Lister Hill Center for National Biomedical Communications to work with the History of Medicine Division to develop innovative ways to expand access to beautiful and fascinating materials in NLM's collection and the historical collections of other institutions.

Lindberg was the prime mover in the expansion of NLM's historical exhibition program, including the addition of the traveling exhibitions which play an important part in outreach to the public. He selected the themes of some major exhibitions and influenced specific topics and artifacts included in many of them. Lindberg was the driving force behind the exhibition entitled *Native Voices: Native Peoples' Concepts of Health and Illness*. His video interviews with American Indians, Alaska Natives, and

Native Hawaiians are the core of the exhibition and could not have been obtained without his personal involvement [27-28].

7. Expanded Access through Partnerships with Publishers and Editors

NLM is dependent on editors and publishers of biomedical literature for essential source material for its services. Editors and publishers benefit from the increased manuscript submissions, subscriptions (if applicable), and citations that result from the inclusion of works they publish in NLM databases. More use of NLM databases increases these benefits.

Nonetheless, there have been sources of friction between the Library and editors, publishers, and the information services industry, e.g., the release of PubMed Central in 2000. In the years just prior to Lindberg's arrival as NLM Director in 1984, the relationships were particularly strained due to differences about copyright and interlibrary loan, as well as an effort to convince the Congress that MEDLINE was unfair competition for the private sector. Lindberg came to NLM intending to defuse this situation and soon identified opportunities for collaborative efforts, including a campaign to increase the number of biomedical journals published on acid-free "permanent" paper. [6,11].

In a wide-ranging chapter, White, Roderer, and Kotzin describe relationships between Lindberg and publishers and editors during his 30-year tenure and highlight accomplishments that resulted from their collaborations [11]. At bottom, there was a good basis for cooperation. Publishers and editors thought NLM should index more journals, and Lindberg agreed with them. The Library could not immediately expand MEDLINE coverage greatly due to costs and size limitations, but Lindberg intended to move in that direction.

As reported by White et al., under Lindberg's leadership, a range of cooperative projects addressed: expansion in MEDLINE coverage enabled by the transition to publisher-supplied electronic citations and abstracts; editors' influence on expansion of trial registrations in ClinicalTrials.gov; various improvements in the quality of the biomedical journal literature; and access to information in low-income countries and in the face of emergencies and disasters. All these activities expanded access to biomedical and health information.

8. Librarians and Expanded Access in a Changing World

Few professions were affected more profoundly - or rapidly - than health sciences librarianship by their clients' access to personal computers, Internet connections, and free Web versions of key professional information sources. The profound impact of technological changes would have occurred in some fashion anyway, but, as Lindberg intended, NLM did indeed "speed this up" for biomedicine and health [3]. NLM information resources provide a foundation for many services provided by health sciences librarians and information specialists. While Lindberg was NLM's Director, that foundation shifted multiple times, sometimes with destabilizing effects. For hospital librarians, these shifts overlapped with changes in health care affecting hospital viability.

As stated earlier, expanding access to biomedical and health information is a multidimensional – and multidisciplinary - undertaking with no endpoint. Librarians and

information specialists play critical roles in establishing and maintaining efficient access to the best resources and tools for their institutions in the face of change and are essential partners to NLM in increasing awareness and use of evolving NLM services. Providing these partners with the education and training to make even greater contributions to health care, education, and research in a changing world was a recurring theme in NLM long range planning throughout Lindberg's tenure.

Lindberg had a high regard for "… the ability and flexibility of medical librarians…You're almost tempted to say they can do anything" [30,p.41]. NLM applauded, encouraged, and supported health sciences librarians as they established and embraced new roles and worked with the library network, academic institutions, and professional associations to provide education and career development opportunities to help them do so. Funk and Holst provide complementary descriptions of NLM's encouragement and support for new roles for librarians and for their education and training respectively [20-21].

8.1. NLM and New and Expanded Roles for Librarians

Carla Funk was Executive Director of the Medical Library Association (MLA) during most of Lindberg's tenure at NLM. She arrived when many MLA members were angry about the Grateful Med marketing campaign and NLM's use of network librarians as a "field force" to expand direct access to NLM databases by health professionals. Funk discusses the long-term positive effects of NLM's support for librarians' role in outreach and training of health professionals, including the transition to a more outward and user-centered approach to their work.

She summarizes NLM grant support for demonstrations of librarians' roles as "informationists" embedded in health care, public health, and research teams. Informationist support from NLM provided early compelling examples of librarians' contributions to research data management. Highlighting her personal interactions with Lindberg over the years, Funk also discusses NLM-MLA partnerships related to librarians' roles in connecting knowledge to EHRs and in promoting health information literacy [20].

Every expansion in NLM programs and services automatically legitimizes and encourages the involvement of other libraries and librarians in related activities within their own institutions. Funk provides the example of NLM's relatively new and important responsibility as the provider of systems used to comply with the U.S. legislative requirements for public access to research results (which MLA strongly supported). NLM and NIH efforts to increase compliance with now-mandatory deposit of articles resulting from U.S. government-funded research in PubMed Central and submission of clinical trial registrations and summary results to ClinicalTrials.gov have engaged and aided librarians in playing important roles in assisting, promoting, and monitoring compliance with these and related requirements within their institutions [20]. As institutional requirements for standards-based research data creation, management, and sharing increase, so do important roles for librarians.

8.2. NLM and Education, Training, and Career Development for Librarians

Ruth Holst, a former hospital librarian, Regional Medical Library associate director, and MLA President, describes the great expansion of librarian education, training, and career development initiatives under Lindberg's leadership and the role of strong partnerships

with the national network, academic institutions, and MLA in the success and amplification of many of them [21]. Examples include: courses related to new NLM programs and priorities, e.g., bioinformatics, health services research, public health, consumer health, disaster preparedness and response; support for scholarships for minority students in master's programs; challenge grants for development of new educational programs; expansion of NLM's existing post-masters Associate fellowship program; and a competitive NLM-Association for Academic Health Sciences Libraries (AAHSL) Leadership Fellowship program to prepare mid-career librarians for directorships in academic libraries.

Lindberg readily supported all NLM initiatives to assist librarians with life-long learning and was instrumental in some of them. These included a highly impactful competitive one-week residential course in medical informatics with a purposely multidisciplinary student body, including librarians, health professionals, and educators and the MLA disaster information specialist certificate program, with courses developed by the national network and NLM [31-32]. In addition to interacting with students in the medical informatics short course for more than 20 years, Lindberg enjoyed his highly valued sessions with NLM Associate Fellows and NLM/AAHSL Leadership Fellows and Mentors. The interactions with Lindberg in these programs demonstrated to many librarians of his respect for them and their profession.

NLM's strong support for a broad array of education, training, and career development assisted U.S. health sciences librarians - and in the case of online offerings many in other countries - in changing the specific ways they contributed to expanded access to biomedical and health information as the world changed around them.

9. Conclusion

By any measure NLM was spectacularly successful in expanding access to biomedical and health information and data under Lindberg's leadership. As demonstrated in the specific examples addressed in this chapter, the many others cited, and some not included in the book, NLM collaborated with many partners to expand access in all its dimensions - more users, more types and volumes of information and data, more effective connections between them, and more people capable of building, maintaining, and enhancing all the necessary connections - technical, conceptual, intra- and inter-organizational, and policy.

Lindberg's vision of what access to health information could be, his understanding of what was required to achieve it, and his belief that NLM could drive progress in all dimensions contributed to the Library's success. Progress along any dimension, e.g., increasing the information available, assisted and interacted with progress on other dimensions, e.g., reaching more users, motivating the development of better access systems.

The tremendous 30-year growth in the amount of information available from NLM was due in large part to an impressive increase in the number of organizations and individuals creating and submitting it. Libraries had been engaged in the distributed creation of standard data for shared automated databases since the mid-1960s. During Lindberg's tenure at NLM, it became a widespread practice (with less rigorous standardization) for: biomedical scientists, e.g., sequences to GenBank; medical and scientific publishers, e.g., citations and abstracts to MEDLINE/PubMed and full-text articles to PubMed Central; authors, e.g., papers resulting from funded research to

PubMed Central; and clinical researchers, e.g., clinical trial registrations and summary results to ClinicalTrials.gov. The drivers included: perceived benefit to the submitter, funder requirements, prerequisites for publication in prestigious journals, legal requirements, and serious consequences for non-compliance with legal requirements.

U.S. government requirements also drove expanded access to some NLM resources, e.g., in cases such as clinical terminology standards in which the Library is the producer or official distributor of the authoritative version of something needed to comply with federal regulations NLM helped to develop.

Lindberg was initially surprised by importance of the public policy dimension in expanding access to biomedical and health information. His position as NLM Director educated him about "…the intimate interplay between policy and science. Some things you just can't do without an explicit public policy, which you cannot get without a democratic process" [30, p.40].

In 2016, Lindberg rightfully gave credit for key policy changes to "the influence of the public in promoting clinical research transparency and free access to government-funded research results," but the decisions he made and the systems NLM built under his leadership played an essential part [33]. Making MEDLINE free via the Internet in 1997 raised public expectations, and the existence of ClinicalTrials.gov and PubMed Central, both released by NLM in February 2000, made new policies feasible, if not easy, to implement.

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Grateful Med: Direct Access to MEDLINE for Health Professionals with Personal Computers

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Abstract: Donald A.B. Lindberg M.D. arrived as Director, U.S. National Library of Medicine (NLM) in late 1984 with the intention of implementing a physician-friendly interface to MEDLINE, a prime example of his interest in making NLM information services more directly useful in medical care. By early 1986, NLM's Grateful Med, an inexpensive PC search interface to MEDLINE useful for health professionals, had joined the group of end-user systems for searching MEDLINE that emerged in the 1980s. This chapter recounts Grateful Med's rapid iterative development and the subsequent campaign to bring it to attention of health professionals. It emphasizes Lindberg's role, the challenges faced by those introducing and using the interface in a pre-Internet world, and some longer-term effects of the effort to expand health professionals' use of MEDLINE during the decade from 1986 to 1996.

Keywords. Donald A.B. Lindberg M.D., U.S. National Library of Medicine, MEDLARS, Grateful Med, User-Computer Interface

1. Introduction

When Donald A.B. Lindberg M.D. was sworn in as Director in October 1984, the U.S. National Library of Medicine (NLM) served health professionals primarily through libraries in hospitals and academic institutions. In general, specially trained librarians used command language interfaces to search MEDLINE, NLM's online index to articles in biomedical journals, and other databases on behalf of "end users", including physicians and scientists. They used commercial telecommunications network connections to reach systems at NLM and commercial database providers. Libraries delivered hard copies of full text articles identified in the searches from local collections or via interlibrary loan through an NLM-directed library network, then called the Regional Medical Library (RML) Network [1].

The number of health professionals searching NLM databases directly was small, but it was increasing. In 1984, NLM and its Network training centers introduced new six-hour "Basics of Searching MEDLINE" classes targeted to health professionals and

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new "Train the Trainers" courses to prepare more librarians to teach these classes to health professionals. By 1985, librarians in many medical schools had begun to teach command language searching to faculty and students and were enjoying an increase in status as a result [2]. In some cases, they provided "user-friendly" interfaces to locally mounted subsets of MEDLINE data for direct use by faculty, staff, and students, thereby reducing telecommunications costs as well as improving access. NLM grants had supported development of some systems for end user searching of MEDLINE subsets, including Paper Chase [3] and MiniMEDLINE [4].

Lindberg arrived at NLM with the intention of implementing a physician-friendly interface to MEDLINE and other MEDLARS databases, a prime example of his interest in making NLM information services more directly useful in medical care. Lindberg viewed the then-rapid uptake of IBM Personal Computers (PCs) as an opportunity to make MEDLINE available nearer the point of clinical decision making, including to physicians not well connected to medical libraries. Professional associations, including the American Medical Association, and commercial database providers had also recently begun marketing online medical information services to individual physicians with PCs.

This chapter describes NLM's rapid development of an inexpensive PC search interface useful for health professionals and the subsequent campaign to bring it to the attention of the target audience. The focus is on Lindberg's role, the challenges faced by those introducing and using the interface in a pre-Internet world, and some longer-term effects of the effort to expand health professionals' use of MEDLINE during the decade from 1986 to 1996.

2. Defining the Goal and Developing the Product

In theory, NLM had at least three options for providing a user-friendly interface to MEDLINE for health professionals with PCs: (1) modification of the ELHILL command language search system resident on NLM's mainframe computer; (2) a front-end search program to interface with the existing ELHILL system; or (3) a MEDLINE CD-ROM product using the format just announced by Philips and Sony in 1984.

Lindberg quickly dismissed the first and third options. Modifying ELHILL's "spaghetti code" would be too time-consuming and unlikely to succeed, as an earlier failed NLM attempt to add a user-friendly option had demonstrated. With typical prescience, Lindberg saw CD-ROMs as a dead-end technology with drawbacks for users, e.g., always out-of-date, requiring local database management, and for NLM, e.g., no direct connection to and feedback from – or ability to count – users. This reasoning also explains his lack of enthusiasm for institutional access to MEDLINE subsets. Lindberg did acknowledge that institutional subsets and MEDLINE CD-ROMs were useful in some circumstances. He encouraged commercial development of CD-ROM products by providing free access to MEDLINE data and technical advice during the development phase and arranging for libraries to assist in product evaluation [5]. Meanwhile, he focused NLM on a front-end software interface to NLM's mainframe search system.

Lindberg defined the goal as a search mechanism that didn't require experience with logging on, the ELHILL command language, or NLM's controlled vocabulary, the Medical Subject Headings (MeSH). It should be easy to use, inexpensive, support growing search sophistication, require minimal documentation, and have extensive online help. In accordance with his strongly preferred approach for any system

development project, the plan was for evolutionary development of successive "smarter" versions of the software, each reflecting user feedback on the previous one [6].

Two months after Lindberg was sworn in as NLM Director, Rose Marie Woodsmall attended a meeting with John Anderson, Director of Information Systems, and Lois Ann Colaianni, Associate Director for Library Operations, among others, and learned that "Dr. L. wants a concrete proposal for end user services" [6,p.164]. She was well qualified for the NLM development team, having worked on the AIM-TWX experiment that first married online searching with commercial telecommunications networks, the release of MEDLINE in 1971, and subsequently on MEDLARS enhancements, training, and user services. Her first assignment was to survey existing operational or prototype end-user search systems and to prepare a report on the state-of-the-art with recommendations for possible NLM next steps, including any existing commercial systems that NLM might endorse or purchase [6].

Woodsmall completed the comparison of twenty-four operational and prototype systems in early February 1985. The MICROSEARCH prototype selected by NLM was the last system to be added to the comparison project. Woodsmall learned about it by chance at dinner with Grace and Davis McCarn, friends and distinguished former NLM colleagues [7]. While at NLM, Davis McCarn had directed the development of NLM's AIM-TWX experiment, MEDLINE, and the NLM ELHILL search system. Recently he had created the MICROSEARCH prototype. It not only met Lindberg's criteria but was designed to interface with an ELHILL derivative. Query assembly was done on the microcomputer, before the connection to the mainframe was made, to keep search costs low. By mid-February 1985, Lindberg and the NLM development team had decided to work with Online Information International (McCarn's company) to adapt the MICROSEARCH prototype to the NLM environment. This was seen as "a not-especially-overwhelming task given its common NLM/ELHILL origin," a more than slight understatement [6, p.165].

Just a year later, in February 1986, Woodsmall and Larry Thompson, then editor of the Health Section of the Washington Post, gave the first public demonstration of Grateful Med, the NLM front end package for IBM PCs, at a Science Writers Symposium. The symposium was an early event in the yearlong celebration of NLM's 150th anniversary. The name Grateful Med, a nod to the rock band Grateful Dead, was Lindberg's choice ("It's just too good to pass up.") from a list of options presented to him [8]. Initial reactions to the name were mixed: you loved it or hated it, but, as time would tell, neither you nor the media ever forgot it. The name proved to be a tremendous asset to another Lindberg priority: educating the public and the Congress about NLM and its programs and services.

Woodsmall and Siegel have recounted the fast pace of iterative development during the year between selection of the base prototype and the release of public version 1, as well as the subsequent two years of refinements, extensions, and necessary institutional adjustments at NLM [6]. Rapid iteration required a highly interactive team approach between NLM librarians, information systems staff, and the prototype developer. Lindberg, other NLM senior staff, NLM Regents, and selected visitors, including members of the NLM Long Range Planning Panels meeting at the Library in 1985, provided periodic review and valuable feedback. Formal multi-phase Beta testing by both target end users and Network librarians occurred from September 1985 to January 1986. In the early years, Woodsmall coordinated feedback from Grateful Med user-testers or "Rose's groupies" as Lindberg called them. He viewed her interactions with them as a gold standard for user involvement in system development.
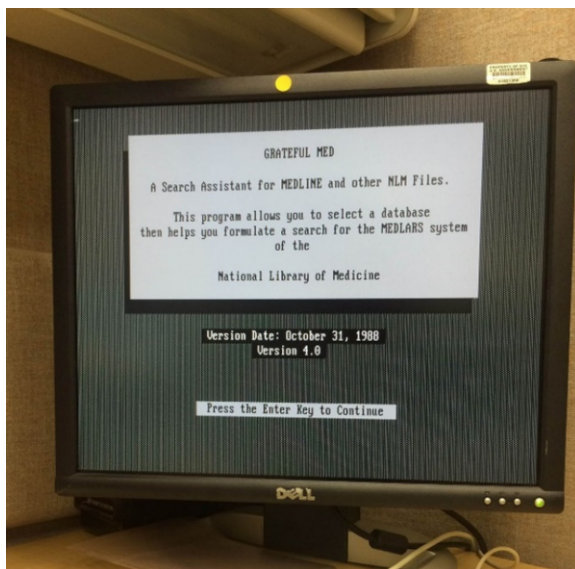
Photo 1: The Grateful Med home screen. Photograph courtesy of Nicole Contaxis.

The methods of interaction evolved, but NLM maintained a feedback loop with users/testers of all new versions of Grateful Med. Eventually there was a suite of locally mounted Grateful Med products: the original PC-DOS, Macintosh, and (short-lived) PC-Windows products; a Grateful Med Search Engine which allowed developers to use the code for Grateful Med's connection to ELHILL while providing a different user interface; a single-copy local area network (LAN) version serving multiple users, and the addition of the Internet as one of the telecommunications options [9]. Lindberg signed off on new features in all versions throughout their lifetimes. He initiated the development of the Search Engine version in 1988 to ease connections between external systems and MEDLINE for Unified Medical Language System (UMLS) researchers [e.g.,10]. As the first Director of the National Coordination Office for High Performance Computing and Communications, Lindberg applauded the use of the National Center for Supercomputer Applications' Telnet TCP/IP source code in developing the LAN version. He also directed NLM efforts to greatly expand access to the Internet and Web-capable workstations. This eventually eliminated the need for locally installed versions of Grateful Med in 1996, when Internet Grateful Med debuted.

3. Pursuing the Target Audience

Users purchased Grateful Med from the National Technical Information Service (NTIS) for a one-time fee of about twenty-five dollars. Software updates were distributed to users free of charge. Users applied to NLM for a logon code for the NLM system. They were billed by the U.S. National Technical Information Service (NTIS)based on the amount of searching done, primarily to cover their fair share of commercial telecommunications charges. With more than 6,500 copies sold in the first 20 months, Grateful Med was a major reason for the big jump in the number of individuals with logon codes for NLM's system from FY 1985 (630) to FY 1987 (at least 9,000) This

increase in users was more than sufficient to require major changes in NLM procedures for issuing codes and providing customer service. It was, however, a tiny fraction of the target audience for Grateful Med, which included hundreds of thousands of health professionals who had a PC or might decide that direct access to MEDLINE was a good reason to obtain one.

As then funded and oriented, the RML Network, NLM's established mechanism for serving individual health professionals, could reach a subset of this audience, primarily those connected to a hospital or an academic institution with a health sciences library, although the goal of the Network was broader. Arguably, those with existing library service had a less serious need for Grateful Med, but many early users were in fact students, faculty, and staff who learned about it from the librarians serving their institutions. A greatly expanded NLM publicity program, initiated by Lindberg, supported by the recently formed Friends of the National Library of Medicine (FNLM), abetted by the buzz around the name Grateful Med, and explicitly authorized by Congress in December 1987, attracted early users, too.

Nonetheless, NLM needed new ways to bring its reasonably inexpensive user-friendly search interface to the attention of many more health professionals. A 1989 report by the NLM Outreach Planning Panel of the Regents of the NLM, known as the DeBakey Report after the Panel's chair, Michael E. DeBakey, MD, saw the combination of new end-user services and active outreach as a powerful way for NLM to pursue its goal of enhancing access to medical information by health professionals who currently lacked library services [11]. The report helped Lindberg obtain additional funding for a new outreach initiative relying heavily on health sciences librarians to reach out to rural, underserved, minority, and unaffiliated health professionals. Between 1990-1992 fifty-eight competitive Grateful Med outreach project awards were made to libraries in academic centers, hospitals, other health care institutions, and professional organizations. These projects were part of NLM's broader outreach programs through the Regional Medical Library Network, renamed the National Network of Libraries of Medicine in 1991 as recommended in the DeBakey report.

In other responses to the report, Lindberg encouraged outreach efforts led by health professionals, hired an in-house marketing manager, and approved flat-rate pricing arrangements for individual users affiliated with a participating institution or professional association. One poorly conceived marketing attempt, a letter about Grateful Med to hospital administrators with no mention of hospital librarians, led some to the erroneous conclusion that Lindberg did not value librarians [12]. It took time for some to become comfortable with the notion of NLM marketing services directly to health professionals.

4. Grateful Med Outreach - Librarian Experience

The Grateful Med outreach projects were meant to demonstrate or teach underserved health professionals how to use Grateful Med as an easy and convenient way to obtain up-to-date medical information for their practices. Although Grateful Med was a relatively easy-to-use system, there were barriers to its adaptation and use. The projects took place in underserved, and often underfunded, rural and inner-city locations. These targeted health professionals often lacked affiliation with a medical library. The project librarians provided training in the use of Grateful Med to search the NLM databases, but also became a conduit to library information and document delivery services. The

"Loansome Doc" feature, added to Grateful Med in 1991, made it easy to send electronic requests for articles identified in searches to cooperating libraries. The feature's name, approved by Lindberg, was a take-off on the hugely popular *Lonesome Dove* television mini-series, based on a book of the same name by Larry McMurtry.

Librarians headed out equipped with twenty-pound "portable" computers, printers, projectors, and hundreds of feet of telephone and extension cords. They provided training to diverse groups including physicians, nurses, dentists, administrators, physical therapists, and other health professionals in the form of demonstrations, formal instruction, and hands-on sessions for small groups or individuals at hospitals, clinics, and public health departments. Exhibits and continuing education sessions at professional meetings provided another way to engage health professionals while they were free of clinical responsibilities.

Training materials developed by NLM were colorful and easy to read. Project librarians could easily tailor them to local needs and training levels from novice to advanced user. On-screen instructions led the user through search strategy construction with Author, Title, Subject, English Only, Review Only, and Journal Abbreviation choices. The search was transmitted to NLM and the search results were sent to the user with the option of including Abstracts. Based on the user's choice of relevant citations, NLM also transmitted suggested MeSH terms helpful for editing a search. This feature gave trainers an opening to discuss searching the database with controlled vocabulary. Loansome Doc could then be used to procure the articles from the Grateful Med project library, often free of charge, or from other cooperating libraries.

The success of Grateful Med outreach efforts was ultimately measured by the number of people who indicated they intended to use Grateful Med when they applied for a logon code for the NLM system. It was often predicated on the "readiness" of both individuals and any institutions concerned. Although Grateful Med was designed as an easy interface to MEDLINE even a novice could navigate with built-in instructions for searching, some health care professionals did not own a personal computer and lacked even basic computing skills.

Lack of computer equipment and inadequate telecommunications systems were major barriers at the underserved hospitals, clinics, and public health departments where many training sessions took place. Rural locations suffered from outdated telephone systems which resulted in difficulty establishing online connections with NLM computers. In many instances the equipment provided by the project was the only computer available for searching Grateful Med at an institution. Medical records personnel or education coordinators often became intermediaries to conduct searches and request documents for others at their institutions because of the lack of computers. Clinicians often cited "lack of time" as a barrier.

A survey of participants in two projects in "Forgottonia," farm-based communities with populations below 30,000 in central Illinois, showed initial field work required follow up and continuation to sustain long-term improvement in information access [13]. The authors concluded that satisfying the information needs of rural health professionals would require multiple approaches over a continuum, and adoption of end-user searching would not be universal. Follow-up projects incorporated lessons learned including such options as advanced sessions, varied training session lengths, award of continuing education credits, extended periods of equipment loan, free document delivery, one-on-one intensive training for personnel acting as intermediary searchers, and working with institutions to formalize relationships with an outreach library. Evaluation showed the benefits of readiness, re-exposure, and reinforcement [14]. In follow up visits, the users

were found to be less computer phobic. There was recognition that computer access was becoming a necessity, and institutions were more likely to have a dedicated Grateful Med computer. Among physicians especially, Grateful Med had gained name recognition and credence through exposure at professional meetings. The follow-up projects also helped to keep health professionals current with the changing Grateful Med software, Loansome Doc, and Internet Grateful Med.

Photo 2: A license plate retired along with Grateful Med after many outreach miles in Illinois and Iowa. Photograph courtesy of Josophine Dorsch.

5. Grateful Med Use - Clinician Experience

Medical students of the early 1980s still knew their way around the many shelves of the monthly Index Medicus, but by then librarians relied on terminal based MEDLARS searching. By the mid-80s paper Index Medicus updates became less relevant to everyone; physicians relied on librarians to search the literature and provide photocopies of journal articles. Shelves and filing cabinets were filled with stapled photocopies of journal articles. Some were organized by topics or by Library of Congress categories, but by the mid-1980s personal computer "database" apps were being used to manage these personal analog libraries. Soon Grateful Med would change all this.

The very early versions of Grateful Med ran on "IBM PC" 360K floppy disks that somehow managed to include a browsable MeSH hierarchy (Mac versions came later). The software made it easy for novice users to work with the formal search terms and modifiers. Although the floppy disks were slow to work with, the software itself was simple to understand and use.

The Grateful Med software was easy to use, but connectivity was another matter. Home digital connections were unheard of, and even hospitals and medical schools relied on modems to transform digital data into analog sounds for transmission on phone lines. Transmission rates were slow; it was easy to read Grateful Med search results as they slowly scrolled down an 80-character wide green text computer screen.

Slow speeds were not the biggest communications challenge, however. These modems had no error correction! Grateful Med worked well until an errant sound on the phone line was converted into an unexpected character or any one of about 128 non-alphanumeric symbols. Modems also varied greatly in their ability to speak to one another; users might have to apply obscure Hayes commands to tweak their modem's behavior.

At that time Grateful Med use took patience and persistence, but the prize was worth the price. In an age when years passed between updates of paper textbooks quality medical care relied on the current medical knowledge available in journals. Prior to Grateful Med, researching a clinical question was largely limited to academic health care centers. Grateful Med was changing the landscape of health care everywhere - including Michigan's highly rural Upper Peninsula (UP).

Grateful Med came to the UP through Michigan State University School of Medicine and the Upper Peninsula Health Education Corporation. These programs funded a rural medical student track including a year of primary care in the town of Escanaba. This rural/academic setting was a great launchpad for taking Grateful Med to medical students, rural physicians, physician assistants, and nurse practitioners.

With support from the National Library of Medicine's Grateful Med Outreach program, demonstrations were performed at medical society and other meetings across the Upper Peninsula. Early training sessions using rural phone lines were challenging. A July 1991 training session with clinicians at Iron Mountain Michigan's VA Medical Center in July 1991 inspired one clinician to reinvent noise filtering! Soon more reliable modems with noise cancellation arrived and Grateful Med became a pleasure to use and teach. Within another year Grateful Med went beyond providing references and abstracts and added the ability to request articles from medical libraries including from Michigan State University's system. Rural physicians began learning what we now call evidence-based medicine.

1996 brought Internet Grateful Med (no more modems!). Locally mounted versions of Grateful Med were retired, but most Grateful Med veterans know it took several years for online Internet successors to approach the efficiency and simplicity of searching on the original Grateful Med.

6. The Impact of Grateful Med

As Lindberg intended, Grateful Med provided direct affordable access to MEDLINE and other NLM databases for many health professionals, as well for students, scientists, health administrators, and journalists. From 1986 to 1996, versions of Grateful Med and the special efforts to promote their use increased the number of individual end users with NLM logon codes from less than 1,000 to more than 100,000. Grateful Med demonstration and training projects increased the levels of awareness and use of MEDLINE and other library services by a diverse group of health professionals, with particular emphasis on the underserved [15]. Lindberg made effective use of maps to show members of Congress how their support of NLM outreach was translating into more people with access to medical information in their states and districts.

Grateful Med was a prominent member of a group of end-user systems for searching MEDLINE that emerged in the 1980s. During the 1980s and early 1990s, direct access to MEDLINE via one or more of these systems and related search training became the norm for students and faculty in U.S. medical schools and many nursing schools. Librarians introduced Grateful Med as an end-user option in the public service settings in academic and hospital libraries, often assuming the cost of searching as part of the library budget. In addition to low cost, Grateful Med had the advantage of availability wherever students and faculty might go to continue their education or careers.

Many health professional users of Grateful Med and other search interfaces relied heavily on the abstracts retrieved from MEDLINE. Although the cost of copies of papers

was an obvious deterrent, clinicians' lack of time to obtain the complete papers (free electronic full text was in the future) and to read them was often a bigger problem. As more clinicians gained access to abstracts in MEDLINE via Grateful Med, Lindberg encouraged the efforts of R. Brian Haynes, MD, Ph.D. and Edward Huth, MD, Editor, *Annals of Internal Medicine* to promote more informative, structured abstracts for clinically significant articles [16]. Lindberg directed NLM staff to make changes necessary to accommodate the first structured abstracts in MEDLINE in 1989 and encouraged NLM staff to track their adoption [e.g., 17]. In 2020, 29 per cent of citations added to MEDLINE had structured abstracts [18].

Structured abstracts were an early step in easing the burden of assessing published evidence for busy clinicians. As health professionals' use of Grateful Med and other interfaces to MEDLINE grew, the benefits, but also the limitations, of MEDLINE as an aid to evidence-based decision-making became clearer. In many cases, clinicians looking for answers to clinical questions were best served by an updated synthesis of best clinical evidence. A well-written abstract to a recent review article might meet this need, if there was one, but that was unlikely for many clinical questions. There were few regularly updated sources of synthesized clinical evidence in the 1980s. The U.S. National Cancer Institute's Physician Data Query (PDQ) system was a shining exception [19]. The growth in the number of health professionals using Grateful Med and other MEDLINE interfaces helped to establish the need and the market for additional sources of synthesized clinical evidence, and many emerged in the 1990s.

 The Grateful Med outreach projects had a significant impact on NLM's Library Network. These projects were the first exposure for many Network librarians to the joys and challenges of working with potential users outside their home institutions. They provided a useful set of lessons learned for future Network outreach initiatives. For example, early success in reaching health professionals at professional meetings led NLM and the RMLs to establish an extensive schedule of exhibits and demonstrations at such meetings in many subsequent years.

The projects extended the services provided by health sciences libraries and fostered increased collaborative activity among libraries. As predicted, they had continuing effects as libraries expanded training and service activities and as the individuals trained continued to use MEDLINE and other NLM services [14]. The opportunity to contribute to improved rural and inner-city health care through the introduction of computerized information retrieval and a link to a health sciences library was a worthy motivation for participating libraries which resulted in benefits for all involved [12].

Teaching use of Grateful Med and other interfaces to NLM databases in librarians' home institutions increased recognition of librarians' expertise. For some librarians, it became the entry point into the information management and evidence-based medicine (then called critical appraisal) curricula within medical and nursing schools.

As it happened, Grateful Med did not have a lasting impact on NLM user interface design, likely to Lindberg's regret. (The Loansome Doc feature is the one exception; it endured in some form until mid-2019.) In 1997, MEDLINE was the first NLM database migrated from the legacy ELHILL search system to Entrez. The Entrez system was a much more flexible search engine developed by NLM's National Center for Biotechnology Information (NCBI) for linked retrieval of gene sequences, MEDLINE records, and some full text on publisher's websites. Entrez's Web-based MEDLINE search interface, PubMed, had a simple search box, similar to the Internet search engines which had appeared after the advent of Web browsers in 1993. It also had useful pre-computed connections among related articles and data.

When MEDLINE became free via the Internet, both Internet Grateful Med, which had interactive search optimization features using UMLS knowledge, and PubMed were available as interfaces. Use immediately increased 10-fold, with the simpler PubMed interface attracting the majority of new users. The ensuing rapid pace of changes and improvements to MEDLINE searching via Entrez/PubMed made it difficult to maintain the Internet Grateful Med interface to that database. Internet Grateful Med played a crucial role in providing access to other NLM databases during the transition away from ELHILL and was retired in 2001.

In comparison to many NLM services, locally mounted versions of Grateful Med had a short history, ended by the spread of Internet access to health professionals, health care institutions, and libraries which Lindberg and NLM had helped to hasten. In February 1986, however, less than 18 months after he arrived as NLM Director, Grateful Med's initial release sent a powerful message about Donald A.B. Lindberg M.D. He was committed to using technology and publicity to expand access to NLM services, he was leading NLM ahead rapidly, and he had a sense of humor.

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Free MEDLINE Access Worldwide

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Abstract. When Donald A.B. Lindberg M.D. was sworn in as Director of the National Library of Medicine (NLM) in 1984, MEDLINE, NLM's online database of citations and abstracts to biomedical journal articles, was searched primarily by librarians trained to use its command language interface. There were fees for searching, primarily to recover the cost of using commercial value-added telecommunications networks. Thirteen years later, in 1997, MEDLINE became free to anyone with an Internet connection and a Web browser. This chapter provides an insider's view of how Dr. Lindberg's vision and leadership - combined with new technology, astute handling of policy issues, and key help from political supporters and influential advocates - enabled a tremendous expansion in access to biomedical and health information for scientists, health professionals, patients, and the public.

Keywords. Donald A.B. Lindberg M.D., U.S. National Library of Medicine, MEDLINE

1. Introduction

On October 11, 1984, Donald A.B. Lindberg M.D. was sworn in as the Director of the U.S. National Library of Medicine (NLM). James Wyngaarden, M.D., Director, U.S. National Institutes of Health (NIH), noted the awesome responsibility of both acquiring and delivering information to those who need it, be they students, practitioners, or researchers. But responsibilities that would "seem like minuses to some would be seen as beckoning challenges to a man like Don." In closing, Dr. Wyngaarden said: "He is a dreamer, he can see the future, but as a decision-maker he is practical, service oriented, and these considerations will rule his judgement. I don't think it's too much for us to expect that he will take the Library into the second millennium that's only fifteen short years away" [1].

As it happened, Don led the institution with dignity well beyond that timeframe, driven by a clear vision of the biomedical information to be made accessible to the varied audiences in the health arena. In his remarks, Don noted that physicians will need up-to-date information as "journals on the shelf will become increasingly too remote for immediate patient care decisions, and the computer-based personal information station will become increasingly useful, comforting, perhaps essential" [1].

This vision was manifested in numerous programs and services Don created and nurtured. My exploration here follows the path that led to NLM's online index to articles in biomedical journals, MEDLINE, being available free on the web. It was a path that

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would require embracing new technology and formulating new policies, as well as overcoming numerous impediments along the way.

Speaking with a JAMA reporter before Don arrived at NLM, I (then NLM Deputy Director) predicted he would bring "perspective on information science that would be really unparalleled in the history of this institution" [2]. What I didn't know at the time was how quickly I would experience that new perspective. Within a week, Don would challenge Dr. Harold Schoolman, NLM Deputy Director for Research and Education, and me to assemble our own office computers. What a change this was for me, but Don believed such a task would bullet-proof me from the computer guys in the future. While Don was a serious, driven, brilliant leader, whenever possible he enjoyed making work fun. I remember telling him early on that past leadership told me my job was to strictly keep the operation running, and not to waste time attending computer-related meetings. Don jokingly would say, "Smith moved from a boss who refused to let him go to a computer meeting….to one who made him build a damn computer" [3].

2. Long Range Plan

Don believed the NLM needed a long-range plan and was surprised no such plan existed when he arrived. While NLM was required to develop plans, they were done mostly as an afterthought, created in record time, and, once developed, were carefully placed on a bookshelf to gather the dust of time. Knowing NLM had done quite well for 148 years without a real plan, Don approached the subject with a good degree of humility. Yet he was convinced his vision of serving health professionals and the general public, not to mention what he saw as a changing role for medical libraries, needed the careful thoughts of others. In developing a planning strategy, initially we met with staff from the National Eye Institute at the NIH and examined their plan, which had been recently developed with external input. This helped in designing our plan's eventual structure of five broad domains [4].

Under the direction of the NLM Board of Regents, the Library appointed panels of experts (some 150 of them) from outside the government to prepare the plan as a road map for NLM's future. Don clearly wanted a bottom-up plan utilizing the views of the very types of people NLM aimed to serve. He opposed the often-traditional approach of top-down planning. He often would say top-down planning might be perfect for attacking the beaches of Normandy, but it was not very good for building the future of an institution like NLM. All five planning panels, in one way or another, envisioned providing access to medical information in new and innovative ways to serve the biomedical community and the general public - the free MEDLINE that was to come to pass certainly filled that bill.

This spirit and vision were exemplified in Don's early Congressional testimony in 1986 when he stated: "The coming years will see dramatic changes in the nature and quantity of information required for providing quality medical care. The magnitude of our continuing investment in biomedical research guarantees this. If we are to reap the maximum benefit from this investment, the Library must be prepared to disseminate the results of this research to all who can benefit from them" [5]. This view was well received by numerous authorization and appropriation committees on the Hill and was advocated strongly by two distinguished friends of NLM: Michael E. DeBakey M.D., eminent surgeon and a prime mover of the 1956 legislation which transformed the Armed Forces

Medical Library into NLM, and Congressman Paul G. Rogers, widely known as "Mr. Health" and an ardent supporter of health information for the public.

3. Information – Commodity or Public Good

As Don Lindberg took the reins of NLM, the information society Daniel Bell had predicted was clearly in full force [6]. Along with it the debate grew even larger on whether information should be regarded as a commodity to be bought and sold, or whether it should be treated as a public good that confers benefits on all of society. Don was well aware of the past battles NLM had encountered over its MEDLARS information retrieval system and soon would become even more familiar with the battle over the pricing of its online services. He quickly realized that the NLM Board of Regents and NLM's own statutory authority which permitted NLM, with the advice of the Board, to offer its services without charge as a public service or upon a loan, exchange or charge basis, could shield the Library from much of the confrontation with the private sector.

In his initial meeting with the NLM Board of Regents, as Director-Designate, in May 1984, the Board of Regents approved the report of its Pricing Subcommittee, prepared in response to a recommendation from the Department of Health and Human Services (HHS). The Board, recognizing the reality of the public/private pressures, thought it was proper for the biomedical community to share with NLM the cost of online services. The NLM would, via appropriated funds, cover the generation costs of building the databases, and the actual users would pay the full cost of accessing the system. There would be no differential pricing by type of user (e.g., commercial, educational). Foreign users, who did not pay the U.S. taxes which covered the generation costs, would pay a surcharge [7].

This position was supported by the Medical Library Association (MLA) and Association of Academic Health Science Library Directors (MLA/AAHSL Legislative Task Force), which regularly met with Congressional committee staff members. These visits had the clear benefit of reminding folks on Capitol Hill the important role medical libraries play in the biomedical information enterprise. Don would often say that you need to keep reminding the public not to forget librarians for they make the information pipeline work. As he put it, "The water flows in the pipe and you forget that someone actually built a reservoir somewhere" [3].

4. Success Requires Multiple Fronts

The Sesquicentennial (150th) Anniversary of NLM in 1986 provided an opportunity to spread the word on the products and services of NLM, and Don was anxious to publicize their value. As he said: "In the past it seems that the NLM has almost been seeking obscurity. A little publicity is appropriate" [8].

When U.S. Representative Paul Rogers stepped forward in early 1986 and formed the Friends of the National Library of Medicine (FNLM) as a 501(c)(3) organization, it was clear a major effort was launched to promote, publicize and support the Library's goals of collecting and organizing scientific information and making it more widely accessible to researchers, health-care practitioners, and the general public. Congressman

Rogers persuaded Jack Whitehead, founder of the Whitehead Institute at MIT, to become the Friends' first Chairman, and soon thereafter a major event was held in December of 1986 with numerous U.S. Senators and some 20 Nobel laureates in attendance. Weeks earlier, Barbara Culliton, a distinguished journalist from *Science*, had asked me a number of penetrating questions about the formation of the Friends. In her December 1986 *Science* article, "Friends' Dance for Library of Medicine," Culliton said "It was the first time anyone can remember that a traditional charity ball has been held for an agency of the federal government" [8]. The FNLM, formed early in Don's tenure, clearly had defied conventional wisdom that such organizations were prohibited from supporting activities of federal agencies

Meanwhile, Lois DeBakey Ph.D., who initiated the Board of Regents outreach efforts in 1984-86, and Dr. Michael DeBakey, who later chaired the Board's Outreach Subcommittee, made significant inroads in reaching the popular press. Ann Landers and Paul Harvey, to mention two prominent media figures, praised the NLM in their writings and on the air. The DeBakey efforts in the early 1990s would catch the eye of Congress when a MEDLINE search, namely "numb chin," was shown on the popular TV show ER. Don didn't miss a chance to mention this before Chairman Porter's Appropriation Committee, pointing out that MEDLINE's searches are geared for public consumption. Don, showing his whimsical manner, told Congressman Porter: "We try to make our systems understand ordinary speech, such as 'numb chin,' and to make the equivalents to the Greco-Roman expressions that medical people and librarians favor" [9]. This exposure to NLM and its purpose to serve the public good did much to blunt the continued efforts by lobbyists to argue that NLM's products were commodities that the private sector alone should disseminate.

5. Technology Advances Spur Progress on Multiple Fronts

The NLM 1986 Sesquicentennial anniversary also was the beginning of major advances on the technology front at the Library. Don's goal of putting more medical information at the fingertips of the nation's health professionals was actively pursued. To the delight of vendors, NLM offered its MEDLINE database to companies distributing information on video discs. One of the earliest players in this CD-ROM field was Cambridge Scientific Abstracts, which was soon followed by 20 or more other companies. Pritchard and Weightman in the UK, seeming a bit over-exuberant, stated, "The excitement generated by the advent of MEDLINE….on CD-ROM disks, had been equaled perhaps only by that which had greeted the introduction of MEDLARS some 20 years earlier" [10].

Don, who seemed to always be a step ahead of other innovators, had already set his sights on a more impactful product, namely the development of a user-friendly search software that would come to be known as 'Grateful Med', a system that was designed for untrained searchers and would run on personal computers [11]. The developmental task required enabling the package to 'shake hands' with NLM's complex ELHILL retrieval system for MEDLINE. In essence, with Grateful Med, people were not required to learn command language to search MEDLINE. Although some laughed at the clever name, Dr. Lindberg, after considering multiple names submitted by staff, simply said "it is just too good to pass up" [12]. Dr. Edward A. Feigenbaum at the 1987 Board of Regents meeting summed up this new "intelligent agent" by saying "the long-term path of computer science is from "how" to "what." We used to have to tell a machine how to

do something; now we can tell it what we want done. … GRATEFUL MED is but the first ministep on that very long path" [13]

The Congress was pleased, health professionals found it useful, and the private sector offered only sporadic opposition. All was well, so it seemed - well not quite. As Betsy L. Humphreys, then NLM Associate Director for Library Operations, succinctly put it: "When I arrived at the National Library of Medicine in 1973, one of the first things I learned was that health sciences librarians are not always pleased with NLM. Most would agree that NLM's leadership and its services have been highly beneficial to the field, but this does not prevent specific NLM actions – or lack of action - from annoying or infuriating some health sciences librarians" [14]. Well, Grateful Med's introduction was one of those times where hospital librarians in particular felt threatened, and Don and I felt we had walked straight into a bee's nest. But the concern lessened as librarians found that Grateful Med and other new technologies provided an opportunity to directly train and assist health professionals and to develop new and innovative outreach programs for the medical community and the general public. Grateful Med certainly made searching easier for doctors, but as Don often said, doctors are not going to be anywhere near as good searchers as medical librarians.

6. The Internet Arrives in Full Force

One bright Friday morning in 1992, Don unexpectedly received a phone call to immediately report to the White House by noon. Somewhat alarmed, he stormed into my office and said in a loud voice "What the hell have you done? They are hauling me down to the damn White House" [15,p.38]. We sat down together and reviewed everything that had transpired that week which might have been viewed as slightly over the edge. Fortunately, when Don returned from downtown, he was smiling and reported that all was well. He had just been appointed to direct the National Coordination Office for the multi-agency High Performance Computing and Communications Office (HPCC), concurrently with directing NLM. He quickly became a major voice for biomedicine as the Next Generation Internet (NGI) began to emerge and empower numerous efforts at NLM [16].

The Internet had been geared initially to areas such as physics research and computer science, but Don's HPCC efforts put the focus clearly on medicine as well. Testifying about HPCC on the Hill, Don was explaining to Senator William Frist M.D. about MEDLINE when the Senator interrupted him and said: "Wait a minute, a day never happened that I didn't do MEDLINE searching when at Vanderbilt" [15,p.56]. Kathy Cravedi, Deputy Director of the NLM Office of Communications and Public Liaison, quickly suggested to Don that he invite the Senator to demonstrate Internet Grateful Med (IGM). So, an FNLM event in June of 1996 featuring Senator Frist was planned which Don felt might essentially secure the endorsement of Congress for MEDLINE on the Internet. The FNLM Conference on Health-Care Applications of the Information Superhighway presented the perfect opportunity to feature Senator Frist performing a search as part of the launch of Internet Grateful Med (IGM). Dr. DeBakey, Chairman of the Board of Regents, also participated on stage – nothing like two surgeons teaming up to promote a new NLM service. At the conference, Senator Frist summed it up this way: "MEDLINE can be critical for doctors in reaching the correct diagnosis and developing a sound treatment plan, resulting in lives saved, limbs spared, and disease prevented, unnecessary treatment avoided and hospitalization reduced" [17]. Reflecting later on the

importance of this event Don said: "You know this Internet is no longer just a political slogan - it's the best communication system this poor old planet has ever seen" [18]. IGM had increased individuals' ability to gain access to MEDLINE data without having to purchase and install copies of GM software.

7. Two Visionaries Meet on the Superhighway

On January 20, 1993 Al Gore was sworn in as the 45th vice president of the United States. As far back as the 1970s as a Congressman from Tennessee he was exploring and promoting the value of high-speed telecommunications. There was the Supercomputer National Study Act of 1986, later followed by the 1991 Gore-crafted High Performance Computing Act which demonstrated the potential advantages the Internet could offer. As Bob Kahn and Vint Cerf - the Fathers of the Internet - expressed it: "Al Gore was the first political leader to recognize the importance of the Internet and to promote and support its development" [19]. Gore coined the phrase 'digital highway,' harking back to his father's efforts in developing the nation's National Highway System while serving as a Senator during the Eisenhower administration. As Chapman and Rotenberg said in their paper "The National Information Infrastructure: A Public Interest Opportunity," a highway metaphor gives the national information infrastructure a concreteness, to employ a pun, that otherwise escapes many technologically unsophisticated listeners when they hear about multi-billion-dollar investments in computer networks [20].

In an editorial in 1995, Lindberg and Humphreys posed the question of "How important will high-performance, …and high-speed communications be for biomedical purposes" [21]. We know now it turned out to be ubiquitous, but at the early stages the challenge was to simply obtain the necessary internet connections for institutions and the general public and demonstrate their use. With Don at the helm of HPCC, and with Gore's perspective on high-speed communications, the two visionaries were in frequent contact, and together their efforts would enhance health care. Importantly health science libraries would be a major part of the future equation.

In the mid-1990s, U.S. President Bill Clinton stated he was going to "reinvent government." The idea was to make the government less expensive, more efficient and to shift it from complacency to empowerment. Vice-President Gore was designated by the President to manage the National Performance Review (NPR). NIH had virtually no interest in this effort, but NLM decided that by being designated a "Reinvention Laboratory" perhaps it could make some lemonade out of this perceived lemon. While much of this was about streamlining operations, it also provided the Library an opportunity to secure some new legislative language allowing it to promote the use of computers and telecommunications by health professionals to enhance access to biomedical information for health care and research.

Don decided this was, of course, an ideal time to intensify our efforts to reinvent the Library's information systems. Our stated goal was to move to a more flexible, powerful, and maintainable computer system that would improve internal processing and provide innovative services to outside users. Many of the internal support systems were addressed by installing a commercial Integrated Library System (ILS) and building a new version of the DOCLINE system for interlibrary loan requests. Also, an effort to find a new retrieval system to replace ELHILL was intensified. NLM simply couldn't continue to maintain the old custom-built software and large mainframe system it had

relied upon for many years. Maintenance was a problem and flexibility was minimal under this legacy system.

Don was already exploring new avenues, and one option involved an interesting trip we took to the University of Massachusetts Health Science Center in Worcester, MA. Though a useful and promising visit, it turned out that the best solution to the NLM retrieval problem was right in its own backyard. David Lipman M.D., Director of NLM's National Center for Biotechnology Information (NCBI), and his talented staff had just developed the Entrez system for searching nucleotide sequences. A part of the Entrez retrieval system, soon to be known as PubMed, clearly had the capability of performing MEDLINE searches and developing important linkages. Don figured here was the final piece needed to offer MEDLINE free over the Internet. However, he emphasized that care would be required as NLM had, for many years, operated within directives and rules set forth by the Office of Management and Budget and the House and Senate Appropriations Committees. They had long required NLM policy to carefully balance the needs of both the private and the public sector.

Don proceeded cautiously, remembering well a previous effort conducted by private sector lobbyists to insert damaging language to eliminate any federal agency control over public use of their databases into a bill to renew the Paperwork Reduction Act. Concerned about the provision, Don and I met with the relevant ranking committee members, Senator John Glenn (D-OH) and Senator Warren Rudman (R-NH). After our conversations, the latter, to our delight, took the unusual and unexpected step of invoking a "stop order" to the bill, which ultimately resulted in eliminating the restrictive language. In speaking with Tom Polgar, Rudman's Chief of Staff, he later explained the Senator's unique action, stating it was simply a testament to what you would call New England crotchety stubbornness.

Each year either during open hearings or in private meetings with appropriations staff NLM would be asked the following: (1) to report on its agreements to support differential pricing for foreign users of our services; (2) to indicate the amount of money we were returning to the U.S. Treasury from online MEDLINE services; and (3) to show the latest breakout of the various users of NLM's online services (i.e., biomedical researchers, health practitioners, medical libraries, the general public, and the pharmaceutical industry.) One concern with free MEDLINE was that without registrations NLM would no longer have accurate information about who its users were.

Don nonetheless felt free MEDLINE should be pursued with vigor. The experience with IGM had showed that this new method of telecommunication, when combined with the software innovation of the World Wide Web, had already reduced our actual costs of providing MEDLINE searching by approximately 80 to 90 percent. Given the clear objective to provide free MEDLINE, an internal NLM Pricing Committee examined the financial issue. The committee found costs could be drastically reduced by (1) eliminating the usage of commercial value-added networks; (2) stopping the registration of users; (3) ceasing the collection of fees, and (4) ending our management arrangement with the National Technical Information Service at the Department of Commerce. By moving to the Internet, the Committee concluded, it could reduce NLM's total costs from approximately $18 million to a manageable $4 million per year. [22]

From an administrative perspective it was clear that NLM could begin its transition plan to introduce free MEDLINE service for Web users, and to make, where necessary, subsidies to health professionals located in areas where there was no local Web access. The next challenge was to quickly garner additional political support, in particular from the Congress. Don got the ball rolling in his March 1997 testimony before Congressman

Porter's Appropriations Subcommittee, where he mentioned that NLM had a new MEDLINE-related service called PubMed. Smiling, he said "the name I attribute to my colleague Dr. David Lipman who has a fertile imagination." Don went on to alert the committee that: "We're actually now exploring whether it might be possible to offer PubMed without charge in the U.S. to those who use our inexpensive Internet connection service" [17].

8. A Notable Citizen Makes a Difference

It is common practice that in addition to formal Appropriations Subcommittee testimony from federal officials that public witnesses appear before the Subcommittee. The premise is that citizen testimony can provide significant additional input into the legislative process and also lend it additional legitimacy. To their credit, the Medical Library Association has provided important oral and written citizen testimony on behalf of NLM on numerous occasions.

On April 15, 1997, the FNLM, then chaired by former Congressman Paul Rogers, requested the Subcommittee to hear from the Chairman of the NLM Board of Regents, Dr. DeBakey. Congressman Dan Miller of Florida, chairing the Subcommittee that day, welcomed Dr. DeBakey by stating they were honored to hear from such a distinguished gentleman. Dr. DeBakey began his testimony praising the NIH and then related how he was involved as part of the Hoover Commission in recommending the establishment of the NLM and its inclusion as a part of NIH. DeBakey spoke of the wonders of the national information infrastructure and especially the Internet and the World Wide Web. That led to what he called the great opportunity, namely: "The Library could provide access to its vast MEDLINE database of references and abstracts to all U.S. citizens without charge on the World Wide Web." After commenting that an educated public is the bedrock of democracy, DeBakey proceeded to his second major point, emphasizing: "I believe that healthcare professionals and consumers should be able to tap into the most recent medical information, for that is a public good, not a commodity" [23].

The committee was clearly impressed to have heard from Dr. DeBakey, Don couldn't have been more pleased, and the theme of free MEDLINE as a public good now was clearly the path going forward.

9. The Vice-President and the Congress Make it all Official

In early June Don and Dr. DeBakey contacted Vice-President Gore to ascertain his possible interest in participating in a press briefing on the Hill to be hosted by Senator Arlen Specter (R-PA) and Senator Tom Harkin (D-IA), chair and ranking minority member of the Senate Appropriations Subcommittee. The request to Vice President Gore was for him to take part in the launching of PubMed, a system that would provide free access to MEDLINE to Americans and others around the world over the World Wide Web. The request was agreed to quickly for it matched perfectly with the vice president's efforts in promoting the importance of the nation's "digital highway" and with the president's initiative in "reinventing government." Both senators were instrumental in the success of the event, with their staff participating in its careful planning and execution.

Fearing yet that some members of the private sector might object to free MEDLINE, an effort to include key people at the ceremony became crucial. To launch MEDLINE free on the Web was to, in effect, turn away from the long-standing agreements NLM had made over the years with Congressional members and of course the ever-present folks at the Office of Management and Budget. As Don amusingly commented: "They (the private sector) may attack me, but they're going to have to take out Varmus, Gore, Specter, and Harkin. I think I'm pretty bulletproof" [15,p.57].

On June 26, 1997, Vice President Al Gore was seated on Capitol Hill before a computer and performed the inaugural free search of MEDLINE. With these profound words he declared: "This development is going to do more than anything we've done in a long time to make people healthy." The vice president searched ear infections, flu shots, and other medical questions, all carried out in an entertaining manner with comic play-by-play with Dr. Lipman, Director of NCBI and leader of the developers of PubMed. All the dignitaries got into the act - Senator Specter: "The superhighway of medical information just became a freeway." Senator Harkin: "Today ER meets the Internet. Searching MEDLINE is going to be on the house." Don Lindberg: "The NLM's debut of free web-based searching could not be timelier" [24].

As expected, the print and electronic media covered the launch. The *New York Times*, the *Wall Street Journal*, the *Chicago Tribune*, the *Washington Post* and many more all praised the development. The *Post* said it simply in its headline: "Medical Research is Made Available to All." Numerous medical journals joined in celebrating free MEDLINE with statements such as: "That event may prove to be a symbolic watershed of 20th century American medicine" [25]. And "Free provision of this enormous resource is arguably the U.S.'s greatest contribution to modern healthcare" [26]. Shortly thereafter, Don would proudly tell Congressman Porter's Appropriations Committee that MEDLINE searching had dramatically increased from a going rate of seven million searches a year to 70 million, and the general public's percentage of searches had gone from almost zero to 30 percent.

On July 25, 1997, the House Subcommittee Report was released, and it provided the important Congressional endorsement of free MEDLINE. Working with the committee staff to finalize this important language was Mr. Bradie Metheny, a staunch NLM supporter and former Director of the Delegation for Basic Biomedical Research. Securing report language was essential, for aside from actual legislation, it is the closest mechanism for conveying clear Congressional intent. The language developed was unambiguous, stating:

> The Committee supports NLM's decision to extend free MEDLINE access within the United States via the World Wide Web. The resulting access to high-quality health information will be an important step to improving public health and will build upon the national investment already made in telecommunications connectivity [27].

The vice president's endorsement and the Committee's report made it all official. Don's vision expressed at his swearing-in ceremony back in 1984 had become a reality. Citizens and the health professionals who served them were now able to access directly the most current and credible medical information available.

The worldwide impact was enormous. At the International Congress of Medical Librarianship in London in 2000, the first held after MEDLINE became free in 1997, the 1,417 attendees from 77 countries passed by acclamation a resolution thanking the

National Library of Medicine "for the enlightened generosity of your policy on access to Medline and other electronic resources via the Internet." In communicating the resolution to Don, Tony McSean, the chair of the Congress, thanked "the U.S. government, the governance of the National Institutes of Health, and yourself personally for transforming at a stroke the quality of information that so many of us can offer to medical professionals and patients. The role of the NLM in the developing global health information system cannot be overstated" [28].

10. Conclusion

John Shaw Billings, M.D., director of NLM's predecessors in the Department of the Army from 1867-1895, created MEDLINE's precursor, *Index Medicus*, in 1879. A medical visionary himself, he said in 1913:

> There is nothing really difficult if you only begin - some people contemplate a task until it looms so big, it seems impossible, but I just begin and it gets done somehow. There would be no coral islands if the first bug sat down and began to wonder how the job was to be done [29].

It was approximately 130 years later that Don Lindberg, a man with a vision and a common purpose, would assume the Directorship of the National Library of Medicine. He, too, had a passion and dedication to transform the accessibility of biomedical information to serve the needs of the nation. His determination, in spite of impediments along the journey, resulted in many achievements for NLM, none greater than free MEDLINE over the Internet. I was honored to have traveled that road with him for 20 years.

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Providing Health Information for Patients, Families and the Public

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Abstract. When Dr. Lindberg was sworn in as Director, the National Library of Medicine (NLM) was providing few resources with information useful to the public, having concentrated efforts towards health professionals and scientists. With his arrival, and that of the Internet in the 1990s, NLM embarked on a research and user-focused path towards providing authoritative health information for patients, families and the public. MedlinePlus, NIHSeniorHealth, and MedlinePlus en espanol delivered health information in a variety of formats using text, still images, audio and video. These resources were supported by NLM advisors and Dr. Lindberg's strong belief that patients and families needed easy access to medical information to be able to effectively care for themselves in illness and maintain the best health possible throughout their lives.

Keywords. MedlinePlus, Consumer Health Information, MedlinePlus en español, Go Local, NIHSeniorHealth, MedlinePlus Connect, U.S. National Library of Medicine, Donald A. B. Lindberg M.D.

1. Introduction

When Donald A.B. Lindberg MD became the Director of the National Library of Medicine (NLM) in 1984, the Library was focusing its collections on publications for biomedical scientists and health professionals, not patients and families. Under Dr. Lindberg's leadership, NLM created and expanded resources for patients and non-professionals, most notably MedlinePlus, MedlinePlus en español, and NIHSeniorHealth. He insisted that these services connect to other NLM resources, especially ClinicalTrials.gov and PubMed. These new services supported his belief that patients and their families need authoritative and accurate information so they focused on information from the government and other authoritative sources. He also strongly supported multimedia resources for consumers, hence agreements for the encyclopedia with images, videos of surgeries conducted at U.S. university medical centers, and illustrated tutorials with audio narration. He initiated a partnership with the National Institute on Aging to create NIHSeniorHealth - including greater accessibility for seniors with features like text resizing and text to speech. As not everyone in for-profit organizations or in government supported this direction for NLM, Dr. Lindberg's leadership was instrumental, as was the support of key members of NLM's long range planning committees and Board of Regents.

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2. Dr. Lindberg, Community Input, and Early MedlinePlus

In his 1984 swearing in address, Dr. Lindberg emphasized the growing importance of computerized information: "For the practitioner of medicine, the book or journal on the shelf will become increasingly too remote for immediate patient care decisions, and the computer-based personal information station will become increasingly useful, comforting, perhaps essential" [1]. During the next decades, his words became true, not only for medical practitioners, but for all members of society. Computers became more personal, local and handheld. As he led NLM towards this vision of computerized information on personal stations, Dr. Lindberg engaged experts through strategic planning panels and the NLM Board of Regents, to provide direction, advice and guidance. He also supported research-based development that guided the initial pilot, release, implementation and improvement of MedlinePlus and related services.

2.1. User Centered Development

Under Dr. Lindberg's leadership, the Library decided to provide MEDLINE free on the Internet in 1997. Providing MEDLINE free to anyone with an Internet connection and a Web browser revealed an appetite for medical information from the general public. After one-year, one-third of PubMed interactions were likely by consumers, not biomedical professionals, although MEDLINE citations and abstracts are not ideal consumer health information sources [2]. With evidence of information seeking by the public, NLM considered how it might effectively meet their information needs in the Internet age. An important research project to determine the answer was a pilot with 40 public library systems, coordinated by NLM's National Network Office. This pilot project, in cooperation with National Network of Libraries of Medicine (NN/LM), the Friends of the NLM, the Kellogg Foundation, the Medical Library Association, and the Public Library Association, gathered feedback on what content and structure would be helpful for libraries to provide health information to their communities. Early MedlinePlus provided these libraries with a resource they could test to see how it fit the needs of their patrons.

The pilot project revealed that health information is always among the top types of information public library patrons request. It also revealed that these patrons would benefit from an easy to use, authoritative, health information service through the Internet [3]. When NLM released MedlinePlus in October of 1998, the website leveraged institutional strengths and Dr. Lindberg's vision of the future [4]. The close partnership of the content and process experts in the Division of Library Operations and the information technology talent of the Office of Computer and Communications Services resulted in a strong initial web site, both in content and structure.

2.2. Board of Regents Policy, Planning Panel, and Public Library Advice

Dr. Lindberg furthered the library's successes through the advice of community leaders. In 1999, the Library's Board of Regents approved a new policy, "NLM and Health Information for the Public." As they had discussed in several preceding meetings, this policy called upon the Library to:

Organize selected authoritative electronic information that is available at low or no-cost, with an emphasis on science-based, nationally applicable resources.

Develop easy-to-use access and delivery mechanisms that promote the public's understanding of health information, drawing on research in lay terminology, graphical and multimedia presentation, etc.

Publicize reputable electronic health information services, including those available from NLM and other sources.

Assist those providing health information to the public to make effective use of electronic services through Internet connections, training, and other means, with an emphasis on those serving minority groups, low income populations, seniors.

Promote integration of NLM services with other electronic services covering regional, state, or local health information [5, Attachment 1].

Building on and amplifying the Board's new policy, the planning panels that Dr. Lindberg convened also addressed consumer information. Specific advice regarding information for patients and the public was included in the "NLM Long Range Plan 2000-2005," which stated:

NLM has historically focused its services and products on an audience of health professionals and biomedical scientists. ...NLM has a responsibility to develop technologies and information systems that meet the public's interest in accurate current, and understandable health information. NLM should partner with federal agencies, voluntary health organizations and others to identify gaps, arrange for development of understandable content, and help the public make effective use of electronic health information [6].

The public library pilot and expert recommendations reconfirmed that the authority and source of health information is very important for patients and the public. From the outset, NLM created selection criteria for resources included in MedlinePlus. Experienced medical librarians at NLM and other medical libraries applied their expertise in evaluating biomedical information resources to create selection guidelines for MedlinePlus. With the proliferation of health information on the internet from organizations, both profit-making corporations and nonprofit educational organizations, it was vitally important to implement guidelines so that MedlinePlus would be a trusted source of health information and the content guidelines continue to be an important part of MedlinePlus to this day [7].

2.3. Research and Operations Collaboration

When MedlinePlus was released in late 1998 with just over 20 topics, they were based on actual user searches of NLM web sites. This collaboration fulfilled Dr. Lindberg's desire that NLM research inform its services. The process was described in this early paper:

Staff of NLM's Lister Hill National Center for Biomedical Communication (LHC) performed mapping and analysis on a five-week sample of searches. The

search log contained 87,423 searches that the LHC staff mapped to 56,905 concept terms using the Unified Medical Language System (UMLS), Metathesaurus, SPECIALIST Lexicon, and lexical programs. Of these, over 8,446 occurred more than once and 2,676 could be mapped directly to NLM's Medical Subject Headings known as MeSH terms. For example, shingles, zoster, and herpes zoster were mapped to herpes zoster; herniated disk and slipped disk were mapped to intervertebral disk displacement.

Once mapped, the terms were ranked by search frequency. The most frequently searched topics included diabetes, shingles, prostate, hypertension, asthma, lupus, fibromyalgia, multiple sclerosis, cancer, and other diseases. Drug topics such as Viagra and Zoloft, and alternative medicines such as St. John's Wort were also frequently searched. A target health topic list of more than 300 was developed based on the analysis of user searches to ensure that the health topics of interest to users were included in MEDLINEplus [8].

This research-based and user-centered process to identify and prioritize the health topics reflected Dr. Lindberg's priorities. He wanted the NLM program divisions, such as Library Operations and the Office of Computer and Communications Systems (OCCS) to collaborate with, and benefit from, the experts in the LHC research Division. This collaboration to identify and prioritize MedlinePlus topics brought together the research expertise of the LHC team and the informatics tools they had created, especially the UMLS, with the staff of operational divisions in the creation and development of MedlinePlus.

2.4. Connecting Users to NLM Information

Dr. Lindberg wanted users of MedlinePlus to be able to find other NLM resources. Staff investigations showed that information seekers want basic overviews at the beginning of their health information journey. Some patients and families develop a deeper understanding of a health condition, because of its serious nature or because it is a long-term chronic condition. Such lay experts have mastered the medical terminology and basic concepts and want to explore the latest scientific research. To serve these patient and family "experts," MedlinePlus provided custom searches from each health topic linking directly to MEDLINE/PubMed. These links were important to connect people to the scientific literature.

When ClinicalTrials.gov was launched in February, 2000, MedlinePlus linked to that important new resource. Once at the clinical trials site, patients and their families and physicians could browse the list of trials, view the inclusion criteria for participants, and decide if they wished to consider participation in a clinical trial. The ClinicalTrials website also linked back to MedlinePlus "to help place clinical trials in the context of a patient's overall medical care" [9, p.36]. These connections fulfilled Dr. Lindberg's desire that NLM services not exist in isolation but connect people to the richness of NLM resources available whenever they wished to pursue them. [10]

3. Dr. Lindberg's Influences as MedlinePlus Evolves and Adds Spanish, Illustrated Encyclopedia and Talking Tutorials

As more people used MedlinePlus, they sent comments, questions and suggestions. To supplement this feedback, staff used new web analytics techniques and tools to gather feedback which drove improvements. Staff conducted some of the first usability tests done at NIH, in partnership with the University of Maryland Human Computer Interaction Lab of Ben Schneiderman. They analyzed search and web use logs. NLM was one of the first government organizations to implement the American Customer Satisfaction Index (ACSI) and the respondents consistently ranked MedlinePlus as one of the top government information websites, bringing it attention from the Wall Street Journal [11], Consumers Reports [12], and others.

3.1. Forming the NIH MedlinePlus Advisory Group

Dr. Lindberg's desire that NLM work closely with government partners supported the creation of an NIH MedlinePlus Advisory Group. This group, composed of representatives from the communications offices or information clearinghouses of other NIH Institutes, facilitated regular NIH feedback and cooperation. This group became an important forum for NLM to communicate the value of MedlinePlus, and show that it improved the ability of the public to find relevant information. Through the members, NLM provided other NIH Institutes with data showing the volume of web traffic NLM directed to their sites. For many years, the Advisory Group provided a regular forum for communication and cooperation, not just with NLM, but among the leaders of public outreach offices of other NIH Institutes [13].

3.2. Growing MedlinePlus with More Topics, Images and Talking Tutorials

When it launched in October of 1998, MedlinePlus provided just 22 topics to serve as the public library pilot, to sense the appetite for such a service, and to gauge the level of effort and funding needed for NLM to grow and sustain an NLM quality service. With the MedlinePlus topic model established and piloted, the most frequent request was for more topics, and the staff worked quickly to meet this user demand. By the end of 1998, there were 44 health topics, and 212 just a year later. By 2000, it provided over 400 health topics and nearly 400,000 unique users viewed over 3 million MedlinePlus pages [14]. NLM had listened to advisors and users in working towards Dr. Lindberg's goal of delivering a respected source of information for patients and their families and friends.

Staff recognized that there were gaps in the information provided by the NIH and other government and authoritative nonprofit sources that MedlinePlus depended upon. They identified these gaps from zero-hit searches, health questions sent to NLM, and requests for additions. Information gaps were especially noticeable in the areas of drug information, symptoms, anatomy, and medical procedures. With Dr. Lindberg's support, MedlinePlus added a patient drug information resource from the US Pharmacopeia and an illustrated encyclopedia of over 4000 articles from A.D.A.M. [9,p.vi]. The illustrated encyclopedia was of particular interest to Dr. Lindberg because of his understanding of how important pictures can be in improving one's understanding of a health problem.

Because he knew Dr. Lindberg was seeking ways to improve patient understanding, Steve Philips M.D. made him aware of talking health tutorials from an organization in Iowa called the Patient Education Institute. These tutorials used simplified language,

included illustrations throughout, and also incorporated a talking feature. Dr. Lindberg recognized that these titles could be an important addition to MedlinePlus and one not likely to be available from another government or non-profit source. The talking feature was especially valued by patients because the audio clearly pronounced medical terms they could see on the screen and repeat as needed. MedlinePlus released the first 30 of these talking tutorials in 2001, and eventually provided 200 of them [15]. They were part of MedlinePlus for many years until the technology used for the talking animations was no longer easily supported.

3.3. MedlinePlus Delivers in Spanish

One of the major enhancements to the MedlinePlus program was to create a Spanish-language version. Dr. Lindberg strongly supported this enhancement, noting the success of the Spanish language offerings from NOAH, the New York Online Access to Health program when bringing it to the Board's attention in their May 1999 meeting [16].

> "There was a discussion of the need for more consumer health information in Spanish, and Dr. Lindberg described "NOAH," a volunteer effort of librarians in New York City to point to sources of medical information for consumers and link to New York resources. NOAH translates information from NIH Institutes into Spanish. NLM's MedlinePlus points to NOAH in a number of places" [5].

MedlinePlus en espanol was also supported by the panel experts who recommended in "NLM Long Range Plan 2000-2005," "Develop easy-to-use access and delivery mechanisms that promote the public's understanding of health information resources. These should be sensitive to cultural diversity issues, educational level, and language (e.g., Spanish)."

Following these recommendations, NLM developed and released a complete Spanish language version of MedlinePlus in 2002. MedlinePlus en espanol was a full-fledged web site that included 500 health topics with links to many government resources, drug information, and an illustrated medical encyclopedia in Spanish [17]. NLM leveraged lessons learned from years of feedback on the English-language site, incorporated them into this new Spanish language site, and hired staff who could maintain the same high standards of selectivity and authority in Spanish. One important function was that the English and Spanish sites crosslinked as completely as possible so that physicians, family members and others could navigate and read in the language of their choice, and easily toggle to the other language. From day one, Dr. Lindberg supported the Spanish language site to grow in parallel with the English site, and it expanded with most of the additions afforded the English language site over the years.

4. Meeting Additional Needs: Images, Seniors, Local Health Services, Electronic Health Records

Following the success of MedlinePlus and MedlinePlus en espanol, consumer health information services from NLM continued to expand and were strongly supported by Dr. Lindberg and the long range planning and Board of Regents advisory groups. In growing the program, NLM added more images, collaborated with the U.S. National Institute on Aging (NIA) and other Institutes to create NIHSeniorHealth.gov, with libraries around

the country to create Go Local, and with health systems and electronic health record (EHR) developers to connect health information to patient portals.

4.1. Adding More Moving and Still Images

Because of the success of MedlinePlus and the excellent reputation of NLM, there were many offers of content, partnerships, and connections from organizations with a variety of products and motivations. Some inquiries wanted the NLM "endorsement," some wanted to increase awareness of their products, some were looking for government funding, and some wanted all of these outcomes. The staff responsible for MedlinePlus reviewed these inquiries to see if any furthered the NLM goals of providing understandable and authoritative health information to the public in a variety of ways, as stated in the *Strategic Plan Addressing Health Disparities 2004-2008*, "Objective 3.1.1 Improve delivery of health information, through the development of easy-to-use information resources such as MedlinePlus that are sensitive to cultural diversity issues, educational level, and language." [18]

One such partnership that Dr. Lindberg reviewed and supported was to provide videos of recorded live surgeries. While not a top request like the drug information already provided on MedlinePlus, there was evidence that some people would want to watch videos of actual surgeries. Dr. Lindberg, willing to give these a try after meeting with the principals at OR-Live.com in 2004, agreed they were a unique new way to provide information to the public. While they were never the most-used resource on MedlinePlus, a pilot proved that some people were interested and found the surgery videos very helpful. After staff worked with the company to agree to supply only videos from Accredited Academic Medical Centers and provide closed captioning in English and Spanish, MedlinePlus eventually provided access to dozens of surgery procedures. Patients who wanted it, now had an audiovisual experience to better understand an upcoming or recent procedure.

In another partnership Dr. Lindberg supported the idea of providing images of dermatological conditions from an organization called VisualDx. This organization had obtained a unique collection of skin condition images from reliable medical school sources with good accompanying descriptions. After meeting with founder Art Papier M.D., Dr. Lindberg supported providing these images as an enhancement to textual information to increase understanding about skin problems. In 2007 MedlinePlus added links to this unique content featuring high quality dermatology images and information on over 150 diseases and conditions. MedlinePlus links to the consumer successor, SkinSight today, in this continued partnership [19].

4.2. NIH Partnership to Serve Older Americans

NIHSeniorHealth was a consumer health service that Dr. Lindberg initiated as a partnership with the U.S. National Institute on Aging (NIA). He discussed the need for health information delivered in a way that resonated with older adults with the Director of NIA, Richard Hodes M.D. They agreed to bring the strengths of each of their organizations together to lead NIH in creating a new kind of website. NLM brought expertise in creating systems and processes to deliver health information effectively and use evolving web measurement techniques to improve them. NIA had strengths in creating information for older people, geared to their specific needs.

NIHSeniorHealth officially launched in October of 2003 on Capitol Hill at a public briefing requested by Senator Tom Harkin of Iowa. The website included many innovations for seniors to facilitate learning about health even as cognition, vision or hearing might be in decline, that were heralded by Drs. Lindberg and Hodes [20]. Staff of NIA and NLM used research on how seniors best gained information from computers and performed live testing with seniors on the prototypes before releasing the website. Dr. Lindberg welcomed feedback from former NLM director, Martin Cummings M.D. and his computer users club of seniors in Florida who tested and provided suggestions for improvement.

NIHSeniorHealth was innovative in many ways. With a click of a button, it would talk and read aloud the text on the page. The text itself was written in the easiest language possible to convey the correct health information. If users needed a larger font, they could use buttons to choose a large, larger or largest font. People could also choose white or yellow text on a dark background, a contrast that improves readability for some vision problems. It was a realization of Dr. Lindberg's view that NLM needed to deliver health information in a variety of ways and did so for the next 14 years.

In 2017, NLM retired NIHSeniorHealth as web browsers had caught up to the needs of people with all abilities and provided many of the capabilities of NIHSeniorHealth for any web site. Innovative in 2003, the features and advantages of a website devoted to the needs of seniors were available to people who needed them through everyday tools; people could get the information from MedlinePlus in the manner of their choosing, whether reading in a particular font size or color or by browser assisted voice [21].

4.3. Linking People to Health Services with Go Local

As MedlinePlus evolved to meet user needs, people were requesting and seeking local health services, in addition to information about health conditions. People wanted to find everything from nearby support groups, health screening services, treatment centers and more. The first Go Local site to launch and connect to MedlinePlus was the pilot of NC Health Info, run by the University of North Carolina at Chapel Hill (UNC-CH) Health Sciences Library [22]. Dr. Lindberg favored the model of working with a capable and progressive partner like the UNC-CH health sciences library and library school to create a working pilot and to use the lessons learned to inform later successes. He attended the launch event of the pilot at the public library in Pittsboro, NC in January 2004 along with U.S. Rep. David Price, several North Carolina state legislators and the state health officer, Leah Devlin.

Even while developing and piloting the system with UNC, NLM staff were simultaneously working with the next site, Missouri. Go Local Missouri was released later that year following an event at the University of Missouri, Columbia. Except for a few sites who chose to maintain their own software system, NLM hosted the Go Local software to ensure consistency in linking to MedlinePlus and to provide the system infrastructure at no cost to each Go Local project. As time went on, more and more organizations committed to create and maintain a Go Local site with a total of 34 projects in 30 states and the District of Columbia, that provided coverage for 46 percent of the US population by 2009. That year, NLM was given an NIH evaluation award to study the effectiveness of the Go Local program.

The evaluation of use data, interviews and other feedback concluded that while the contributing partners were dedicated to the mission of providing health services connections, the overall program wasn't sustainable for the long term and there were viable and more prominent ways for people to get health services information. As NLM summarized in 2010, "In today's Internet environment, there are many comparable resources to an Internet health services directory such as Go Local. Internet search engines that people use daily, such as Google, Yahoo, and Bing, bring a wide range of health services listings to users, and many offer added value that Go Local cannot. These sites list provider-level directory information and can collect user reviews. Today's health insurance sites give insured users local practice details, such as hours, languages, fees, and quality ratings based on provider or facility performance measures that would require too much labor-intensive manual collection for Go Local to provide, but that our users have said they want in a health services site." [23]

During his tenure, Dr. Lindberg often demonstrated the importance of ceremony and hospitality in recognizing contributions and honoring colleagues. At the close of the Go Local program, he supported and spoke at a reception for all the Go Local partners at the 2010 Annual Meeting of the Medical Library Association, in Washington D.C. He and other library leaders acknowledged the shared goals in starting the program and the reality of the time to end it. One of the partners, M.J. Toohey, Associate VP at the Maryland Health Sciences and Human Services Library, highlighted that for her library, one of the most positive outcomes of Go Local was the goodwill, recognition, and new partnerships they developed at their institutions, in their community and state. Other Go Local leaders echoed this theme that being part of Go Local had strengthened important community connections.

4.4. Connecting from Patient Portals of Electronic Health Records

As EHRs became more common and were incentivized by the U.S. government's meaningful use program, the staff of MedlinePlus moved to leverage MedlinePlus's highly organized corpus of consumer health information to be delivered to patients through patient portals. By leveraging the UMLS and its clinical vocabularies and mapping health topics to terms used in EHR systems, patients could directly link to MedlinePlus information on tests, drugs and conditions.The success of this effort resulted from an initial pilot with highly competent and motivated partners, in this case, the Institute for Family Health in New York, their Director, Neil Calman M.D., and their EHR provider, Epic Systems. With the support of Dr. Lindberg, NLM worked closely with the Institute for Family Health to create systemic connections so that a patient in Epic's MyChart could quickly find information related to any problem mentioned in their record. Called MedlinePlus Connect, this program was recognized in 2011 with a HHS Innovates award and continues to use web and medical terminology standards to provide this service today to many health organizations via many EHR products and other systems.

5. Lasting Legacy in NLM's Consumer Health Services

During his long tenure, MedlinePlus and its related products served to further Dr. Lindberg's vision of reaching patients with quality information, not just in text, but with sound, images, animations, and in their own language, whether simplified English, Spanish or another language. As he had hoped, MedlinePlus connected to and integrated

with other NLM resources, including PubMed, ClinicalTrials.gov, Genetics Home Reference, and others, often using the results of NLM research and development to accomplish this integration.

The consumer information program also followed his vision of piloting and experimenting with new ways to reach people. Staff worked to continually evaluate the effectiveness of functions and services, keeping what worked, such as Connect, and ending programs that were inefficient to effectively maintain, were supplanted by new technology, or where patients and their families were better served by other NLM or outside services. By 2014, more than 400 million visitors viewed over one billion pages of information on MedlinePlus, making it a leading resource for people the world over. Dr. Lindberg's view that patients want to learn about their health for themselves, learned from his early experiences, remains true today.

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An Active Contributor: Dr. Lindberg and NLM's Historical Programs and Services

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Abstract. Donald A.B. Lindberg M.D.'s interests extended far beyond his scientific expertise into the arts and humanities, as evidenced, for example, by his love of opera, his talents in photography, and his affection for history. It is therefore not surprising that he had a strong interest in the National Library of Medicine's historical programs and services, going beyond supporting these activities to becoming actively involved in some of them. The subject of this essay is Dr. Lindberg's contributions to these programs and services, which may be grouped under three main headings: placing greater emphasis on more contemporary history, promoting the digitization of historical materials to increase access, and enhancing outreach through an exhibition program.

Keywords. History of medicine, history, historical collections, digitization, exhibitions, U.S. National Library of Medicine, Donald A.B. Lindberg, M.D.

1. Introduction

The interests of Donald A. B. Lindberg M.D., Director, U.S. National Library of Medicine (NLM), extended far beyond his scientific expertise into the arts and humanities, as evidenced, for example, by his love of opera, his talents in photography, and his affection for history. One reflection of his broader interest was his decision to sponsor and help organize three symposia on medicine and the arts at NLM, beginning with a program on "Medicine and the Arts: Two Faces of Humanity" on April 12, 1986 as part of the Library's Sesquicentennial Celebration. This event was followed by symposia on "Images of the Health Professions in the Popular Arts" in 1988 and "The Medicinal Muses: The Therapeutic Value of the Arts" in 1990. Dr. Lindberg also arranged for several exhibitions on medicine and visual art during his tenure.

It is therefore not surprising that Dr. Lindberg had a strong interest in the NLM's historical programs and services, going beyond supporting these activities to becoming actively involved in some of them. The subject of this essay is his contribution to these programs and services, which may be grouped under three main headings: placing greater emphasis on more contemporary history, promoting the digitization of historical materials to increase access, and enhancing outreach through an exhibition program.

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2. Placing Greater Emphasis on 20th-Century History

Dr. Lindberg's interest in history was broad, but he was especially committed to having the Library increase its efforts to document and interpret more recent developments in the health field, specifically those of the 20th century, given the significant developments in medicine and science since World War II and the advancing ages of many key participants. The Library's general collection, of course, covered relevant contemporary printed and electronic materials relatively comprehensively. However, it was the responsibility of the History of Medicine Division (HMD) to collect and house manuscripts and archives and prints and photographs. The Division's audiovisual collections also covered roughly the first three-quarters of the twentieth century. Dr. Lindberg not only encouraged and supported the expansion of these efforts in documenting the 20th century but took an active role in the process. He additionally promoted public programs, research, and publications on recent medical history.

From early in his tenure at the Library, Dr. Lindberg worked with HMD and its Chief, John Parascandola Ph.D., to place increased emphasis on collecting the archival records of important institutions and the personal papers of key scientists and health professionals. Because of his knowledge of contemporary medicine and his many contacts in the field, Dr. Lindberg was able to identify and facilitate the acquisition of relevant collections. He also promoted the recording of the history of contemporary medicine through conferences and publications.

An excellent example of Dr. Lindberg's contributions with respect to institutional history and records is the key role he played in the documentation of the Regional Medical Programs (RMP) initiative. The RMP were conceived as a "Great Society" project of U.S. President's Lyndon B. Johnson's administration and had the goal of bringing high-quality medical care to the American people by linking health research with community health needs on a regional level. Centers of excellence that encompassed medical schools, research institutions, and hospitals were created under the program. The President's Commission on Heart Disease, Cancer and Stroke, chaired by Michael E. DeBakey M.D., produced the blueprint. The RMP became operational in 1966 but began to decline in 1974 due to cuts in the U.S. federal health care budget. Independent RMP operations had ceased by 1976 [1].

Dr. Lindberg was involved with the University of Missouri RMP as a young faculty member and developed several innovative computer applications that contributed to the success of the program. As a result of his experience, Dr. Lindberg came to greatly respect the RMP and always regretted its demise. When he came to the Library, he saw an opportunity to preserve and tell the history of this significant program and the lessons to be learned from it [2].

Based on his own experience and knowledge, in 1991 Dr. Lindberg identified key individuals involved in the development of the RMP and arranged to conduct oral histories to preserve their recollections of the program. With assistance from HMD and the Lister Hill National Center for Biomedical Communications (LHC) Audiovisual Program and Development Branch (APDB), the selected participants were brought to NLM for videotaped interviews, some conducted by Dr. Lindberg himself. The interviews, then, were deposited in the Library's collection. Dr. Lindberg used this opportunity to obtain manuscript materials related to the RMP from the participants to add to NLM's collection [3]. Lois Ann Colaianni M.L.S., then NLM Associate Director for Library Operations, also had previous experience in an RMP program and solicited and compiled documentation of RMP projects involving medical librarians.

In addition to documenting the RMP, Dr. Lindberg decided that its history should be told in various formats. He arranged for a conference at NLM on the history of the RMP initiative in December of 1991 and for the APDB to produce a video history of the program [4]. He hired historian Steven Strickland Ph.D. to write a history of the RMP. Strickland's *The History of Regional Medical Programs: The Life and Death of a Small Initiative of the Great Society* was published in 2000 [5].

Not surprisingly, Dr. Lindberg took an active interest in the history of biomedical informatics, the field in which he had a distinguished career. He arranged for the library to host a conference on the history of medical informatics in November 1987 [6]. Dr. Lindberg persuaded another pioneer in the field, Morris F. Collen M.D., to undertake a project on the history of computers in medicine with support from the Library. The result of this effort was Collen's book, *A History of Medical informatics in the United States, 1950 to 1990*, published in 1995 [7]. Dr. Collen also deposited his personal papers at NLM.

In addition, Dr. Lindberg promoted preserving and providing access to the historical records of health services research, another relatively young research field. Before coming to NLM, Dr. Lindberg directed a National Special Emphasis Center on Health Care Technology at the University of Missouri, funded by the National Center for Health Services Research. The 1993 National Institutes of Health (NIH) Revitalization Act created a National Information Center on Health Services Research and Health Care Technology (NICHSR) at NLM to improve "the collection, storage, analysis, retrieval and dissemination of information on health services research, clinical practice guidelines, and on health care technology" [8].

Dr. Lindberg recognized the importance of documenting the history of this discipline. In 2000, NICHSR and the LHC worked with HMD to produce *Health Services Research: A Historical Perspective*, a video history of the field. The following year, NICHSR convened an ad hoc advisory committee of health services researchers, historians, and librarians to advise NLM "on appropriate next steps in its initiative to document and preserve the history of health services research" [9].

As aforementioned, Dr. Lindberg encouraged the expansion of the NLM collection of personal papers of contemporary health professionals and biomedical scientists. He took an active role in soliciting these collections. For example, it was Dr. Lindberg who first approached Nobel Laureate Joshua Lederberg on behalf of NLM and persuaded him to contribute his large collection of personal papers to the Library [10]. Lederberg shared the 1958 Nobel Prize in Physiology or Medicine for his discoveries concerning genetic recombination and the organization of the genetic material of bacteria.

Among others, Dr. Lindberg helped NLM acquire the personal papers of Dr. DeBakey and biochemist Dr. Marshall Nirenberg (the National Institutes of Health scientist who shared the Nobel Prize in Physiology or Medicine in 1968 for his work in breaking the genetic code). Dr. Lindberg also promoted increased access to these modern manuscript collections through digitization as discussed in the following section.

Given Dr. Lindberg's interest in visual arts, it is not surprising he also actively supported the expansion of NLM's collection of public health and biomedical posters, especially recent ones. In 1987, HMD began a vigorous campaign to collect contemporary posters, with special emphasis on AIDS, with the aid of consultant William Helfand, an expert on this genre [11]. NLM prepared a traveling exhibition of posters from its collection in 1990 that was eventually circulated to ten museums and medical libraries [12].

3. Digitization of Historical Materials to Increase Access

Dr. Lindberg recognized it was important not only to collect and preserve the historical record, but also to provide access to it. Given his technical background in computers and medicine, Dr. Lindberg clearly understood that the digitization of library materials was the best way to make them more accessible to users. He initiated and/or supported several important initiatives in this regard.

One highly visible effort was the *Profiles in Science* project. From the time he first talked to Dr. Joshua Lederberg about donating his personal papers to the Library, Dr. Lindberg envisioned and discussed digitizing these papers so that they might be accessible to remote users [10]. This idea led to the creation of *Profiles in Science*, a pioneering digital library Web service that "brought together the best in archival practices with state-of-the-art technology to present to the public a look behind the sense of scientific findings and the unpublished writings, letters, and lab notes of great scientists." HMD staff worked with the LHC to establish a production operation for scanning and creating metadata for the manuscripts of important scientists, and the Profiles in Science website debuted in September 1998 [13,p. iv,8.].

Papers related to Dr. Oswald Avery, the scientist at the Rockefeller Institute for Medical Research who provided the first evidence that DNA was hereditary material in the 1940s, were the first to become accessible on the website. The originals of most of the items in this collection are held in other archives, reflecting Dr. Lindberg's view that the Profiles in Science site should include materials held by other institutions. The papers of Dr. Lederberg contained materials related to Avery, including copies of originals in the Rockefeller Archive Center assembled by Dr. Lederberg during his tenure at the Rockefeller Institute. Dr. Lederberg thought that Dr. Avery should have received a Nobel Prize for his work and encouraged NLM to make his papers available first. The other source for the Avery materials was the Tennessee State Library and Archives. The Lederberg papers themselves were the next materials to be made available on the site [13-14,p.4-5,15].

The Profiles in Science site continued to add collections over the years, and now includes papers from 39 different individuals, encompassing materials housed at NLM and at various other archives. Most of the individuals featured are famous scientists, including Nobel-Prize winners such as: Dr. Lederberg; Dr. Christian Anfinsen; Dr. Nirenberg; Dr. Martin Rodbell; Dr. Harold Varmus; and Dr. Barbara McClintock. In addition, the site includes the papers of non-scientists who played key roles in advancing biomedical science and medicine, such as philanthropist-lobbyist Mary Lasker and U.S. Congressman John Fogarty. The papers of such public health leaders as Surgeon General C. Everett Koop M.D. and epidemiologist and public health administrator Dr. Fred Soper also are included on the site. A selection of public health posters has been added [16].

Another important addition to the Profiles in Science site is the collection of Reports of the U.S. Surgeon General. Dr. Parascandola. then the Public Health Service Historian, proposed to Dr. Lindberg that the Library scan all of the Surgeon General's Reports, beginning with the influential 1964 report on smoking and health. Dr. Lindberg readily agreed to Dr. Parascandola's proposal, and NLM's Library Operations (LO) worked with the LHC and the Office of the Surgeon General to identify and scan all retrospective reports and add them to the Profiles site [17,p.11]. The project was expanded to include additional materials, such as images and other documents related to the Office of the Surgeon General [18].

Dr. Lindberg also promoted the digitization and creation of machine-readable catalog records for various parts of NLM's historical collection. One significant example is the digitization of items from the prints and photographs collection. This effort began in the mid-1980s with the creation of a pilot videodisk with about 1,000 images and descriptive records of pictures. HMD then worked with the LHC on a project to put the rest of the prints and photographs collection on videodisk and to link the images to online records. An assessment suggested the videodisk technology was expensive and time-consuming and would not be the best way to distribute the images. So, a decision was made to create a website with the images and records. In 1994, Dr. R.P.C. Rogers of the LHC prepared the first version of the Images from the History of Medicine website [14,p.18] Improvements were later made to the site to allow users to manipulate images in various ways and to download high resolution copies [19-20]. The Images site currently contains digital images and catalog records for more than 70,000 items [21].

Dr. Lindberg launched NLM's digitization of pre-1966 indexing data, with strong encouragement from Dr. DeBakey. Dr. Lindberg believed that it was important to go back to at least the 1940s because there were important advances that came out of World War II and the expanded postwar funding for biomedical research. Thus, the literature was potentially useful for current biomedical research as well as for historical scholarship. Dr. Lindberg asked LO to undertake this task [22].

More than 307,000 citations from the 1964 and 1965 *Cumulated Index Medicus* were released in a new OLDMEDLINE or OLDMED database in 1996. The 1964 and 1965 citations were converted from machine readable files available from the Deutsches Institut fur Medizinische Dokumentation und Information, then the German MEDLARS Center. Citations from the 1960-63 volumes of *Index Medicus* were keyboarded and added next. Contracts were awarded to keyboard 1957-59 data from the *Current List of Medical Literature*, with Lakota Technologies, a Native American organization, receiving the contract for the 1957 data. Eventually records going back to 1946 were added, and all OLDMEDLINE records were incorporated into MEDLINE [23-26].

In general, Dr. Lindberg was supportive of all efforts to digitize materials in the historical collections [22]. One of the most important of these projects was the digitization of the *Index-Catalogue of the Library of the Surgeon-General's Office*. John Shaw Billings, head of the Surgeon General's Library of the U. S. Army (predecessor of NLM) initiated the publication of a catalog of the Library's holdings (including books, journals, journal articles, dissertations, etc.) in 1880. This massive project required fifteen years just to complete the first series, which ended in 1895. By that time, the Library had added many more titles and a second series began, followed by a third and a fourth. With the fourth series still in progress in the 1950s, the backlog of indexing had become so great that NLM decided to discontinue the publication in favor of producing monthly indexes and quarterly catalogs with annual cumulations. The last volume appeared in 1961, bringing the total to 61 volumes. *Index-Catalogue* was, and remains, a treasure trove of bibliographic information for historians of medicine, but it was not widely available in libraries and was very time-consuming to search [27].

The American Association for the History of Medicine's (AAHM) Electronic Media Committee initiated the project to digitize the *Index-Catalogue*. In 1997, the Wellcome Trust and the Burroughs Wellcome Fund awarded grants to support pilots to determine feasibility and to suggest possible conversion approaches. AAHM presented the results to NLM in 1998, and the Library agreed to support the costs of digitization of the data, system software, and free Internet access. The conversion began in 1999 and was completed in 2002. IndexCat, the online version of the *Index-Catalogue*, contains all of

the citations in the 61 volumes of the publication, totaling more than 3.7 million references, making this information much more accessible and searchable online [23,26,28].

During Dr. Lindberg's tenure as NLM's Director, many other historical materials were digitized and made available online. For example, by the end of 2010, 107 interviews from HMD's Oral History Collection, consisting of more than 13,000 pages of transcripts and 80 hours of audio content, had been digitized and made available on a new Web interface. Additional interviews continued to be added to the site [29].

Another important project was the digitization of the Food and Drug Administration (FDA) Notices of Judgement Collection, an archive of the federal notices of judgement (a summary of the final outcome of a court case) for manufacturers and products prosecuted under U.S. food and drug law. The Notices of Judgement are useful resources for historical research and can also lead users to a large collection at NLM of the physical evidence used to prosecute each case [30]. NLM also has digitized hundreds of items from its audiovisual collections and made some of them available, along with historical essays about them, on its Medical Movies on the Web site, later renamed Medicine on Screen [31].

Dr. Lindberg was enthusiastic about NLM's collaboration with other institutions on several digitization projects. For example, in 2004 the Library signed a Memorandum of Understanding with the Wellcome Trust and the United Kingdom Joint Information Systems Committee to work together to make thousands of back issues of historically significant biomedical journals freely available in PubMed Central. The agreement included a donation of $2.2 million to NLM to support the digitization process, which involved soliciting volumes to digitize from other libraries to avoid any damage to NLM's archival collection [32]. A subsequent agreement with the Wellcome Trust provided an additional $1.2 million for digitizing biomedical journal articles, this time using NLM materials [33]. NLM also joined the Medical Library Heritage Project, a cooperative effort (with funding from the Alfred P. Sloan Foundation) to digitize historical materials from the collections of a consortium of libraries. The goal of the project, which began in 2010, was to digitize books and journals documenting the development of American medicine from the 17th to the 20th century.

The NLM units involved in the project were HMD, the Public Services Division, the Technical Services Division, and the Office of Computer and Communications Systems. The project was NLM's first effort to develop in-house capacity to digitize its collections for long term access and preservation [34, p.8,35, p.7].

A final example of the digitization efforts Dr. Lindberg strongly supported is the "Turning the Pages" project, suggested by then-NLM Deputy Director Kent Smith after he viewed the technology at the British Library (BL). HMD and LHC cooperated with the BL to install "Turning the Pages" at NLM in 2001, using the combination of computer animation, high-quality digitized images, and touch screen technology invented by BL to simulate the action of turning the pages of a book. The first book available at NLM that used this technology was Elizabeth Blackwell's beautifully illustrated *Curious Herbal*, published between 1737 and 1739. Works added to "Turning the Pages" subsequently included Andreas Vesalius' groundbreaking anatomical treatise *De Humani Corporis Fabrica* (1543) and the Edwin Smith Papyrus (an Egyptian surgical text from about 1600 BC) [36,17,p.18,37,p.16-17]. LHC reimplemented the technology to make "Turning the Pages" available via the Web. The onsite "Turning the Pages" display is a part of the Library's expanded exhibition efforts, the subject of the following section.

4. Enhancing Outreach Through an Exhibition Program

HMD, working with the LHC's APDB, had long developed two or three historical exhibitions a year for the Library's front lobby, displayed in several modest exhibition cases. HMD did not have a dedicated staff to produce these exhibitions, but relied on staff responsible for other activities, often working with outside consultants and organizations. Dr. Lindberg took an interest in these exhibitions from the time that he arrived at NLM. He also saw the potential for outreach that an expanded and improved exhibition program could offer and eventually took implementation steps [10, 22, 38-39].

One of the reasons Elizabeth Fee Ph.D. was hired for the position of Chief of HMD in 1995 was Dr. Lindberg's interest in her experience in developing exhibitions. For example, Dr. Fee recently had served as the co-curator of the highly acclaimed "Garbage! The History and Politics of Trash in New York City" exhibition, on display at the New York Public Library from November 12, 1994 through February 25, 1995 [22, 40-41].

Soon after Dr. Fee arrived at the Library, an opportunity arose for NLM to produce a major exhibition of the type Dr. Lindberg envisioned. Esther Sternberg M.D., then a Senior Scientist and Section Chair at the U.S. National Institute of Mental Health (NIMH), was working with the John D. and Catherine T. MacArthur Foundation on planning an international meeting on the interactions among neurophysiology and the functioning of immune systems. At the time, some sectors of the scientific community were suspicious of the idea of a connection between the brain and the immune system, and between emotions and disease. Yet, the decision was made to hold the Third International Congress of the International Society of Neuroimmunomodulation at the Natcher Center at NIH in November, 1996. Since NLM is just across the street from the Natcher Center, Dr. Sternberg believed it would be an ideal place to hold an opening reception. When she consulted with Sheldon Cohen M.D. of the National Institute of Allergy and Infectious Diseases, then a scientific scholar at NLM, he suggested the Library would also be an excellent venue for an exhibition on the mind-body connection, which had a long history in medicine. Dr. Cohen mentioned NLM had recently hired Dr. Fee, and she was looking for a topic for a planned new exhibition program [40].

Dr. Cohen introduced Dr. Sternberg to Dr. Fee, and the two of them agreed to collaborate on the project, with HMD coordinating the development of the exhibition. Recognizing the demands this project (which had to be completed in several months) placed on HMD staff, Dr. Fee hired Patricia Tuohy, an exhibition specialist, as a short-term contractor to assist with the exhibition, which opened in October 1996. Historians Dr. Anne Harrington and Dr. Theodore Brown served as visiting curators.

Dr. Lindberg took an active interest in the exhibition, and NLM provided partial support for it. At one point, one of the NIH Institutes strongly objected to the inclusion of a section on Freud because the views discussed were no longer accepted by scientists. Dr. Lindberg firmly resisted efforts to change the exhibition, arguing that the content should accurately portray the history of the subject and one "cannot take Freud out of history." Unlike previous HMD exhibitions, the scope and scale of "Emotions and Disease" and its polished feel resembled a Smithsonian exhibition, and it occupied not just the front lobby, but also the Library's rotunda [22, 40,42-44]. It even garnered a full-page glowing review in the Weekend Section of the *Washington Post* [45].

Dr. Lindberg reacted enthusiastically and asked Dr. Fee to produce another major exhibition. She extended the contract of Ms. Tuohy to assist with a new exhibition, titled "Frankenstein: Penetrating the Secrets of Nature." Dr. Lindberg was enthusiastic about the topic and behind some of the themes and artifacts selected [22, 44]. The exhibition opened on October 30, 1997 with an opening costume party reception featuring as a special guest Sara Karloff, the daughter of Boris Karloff, who played the monster in the famous 1931 Universal film [46,13,p.12-13]. At the reception, Dr. Lindberg commented: "This thought-provoking exhibit is both timely and timeless. On Halloween eve, its theme is entirely appropriate, of course. But this exhibit explores some of the fundamental questions of all time. Why has the public at times feared science? Have changes in communication technology made the public feel close to the center of decision-making regarding science policy. If so, has this allayed their fear of science?" [46].

Guest curator Dr. Susan Lederer observed: "Unlike in Mary Shelley's day, when access to medical and scientific knowledge was limited to a wealthy and educated elite, today we have unparalleled access to such information through institutions like the National Library of Medicine, through the popular media, and through the World Wide Web. The challenge is how to navigate this ocean of information to educate ourselves about developments in biomedical science, in order to make responsible decisions" [46].

Subsequent exhibitions followed this pattern of being on display for about a year and making use of space in both the front lobby and rotunda. However, HMD continued to mount smaller exhibitions in the front lobby area and within the HMD Reading Room [47]. The next major exhibition, "Breath of Life," about asthma, opened on March 23, 1999. It was the largest exhibition mounted at NLM up to that time. Once again Dr. Lindberg had to run interference when collaborating NIH institutes demurred about the inclusion of empirically falsified ideas - because the latter were needed to complete the exhibition's historical record [22,40,25,p.16].

The pattern of installing a new large-scale exhibition in the rotunda approximately once a year continued and evolved into a formal distinct exhibition program. In 1998, Patricia Tuohy was hired as head of the exhibition program on a permanent basis. The informal exhibition program was officially made a section, the Exhibition Program Section, under a reorganization of HMD in 2008 with Ms. Tuohy as its head [44]. Exhibitions were historically based, but also discussed relevant contemporary aspects of the subjects covered. The description of the program on the NLM website states the goals of the program are to "stimulate enthusiasm for history and encourage people to learn about medicine, themselves, and their communities," "to enhance awareness and appreciation of the NLM's trusted health information resources,' and to "advance public understanding of how the past informs the present – and can shape the future" [48].

Dr. Lindberg continued to play a significant role in various aspects of the exhibition program. For example, he was the prime mover in the selection of some exhibition topics, such as: "The Once and Future Web: Worlds Woven by Telegraph and Internet" (2001-2002); and "Native Voices: Native Peoples' Concepts of Health and Illness" (October, 2011-July, 2015), which is described by Wood and Siegel [49].

When the "Changing the Face of Medicine: Celebrating America's Women Physicians" exhibition (October 2003-November 2005) was being planned, Dr. Lindberg recognized there could be differences of opinion about which female physicians should be featured. To minimize controversy, Dr. Lindberg arranged for the formation of a distinguished ad hoc advisory committee (both women and men), chaired by surgeon, former Olympic gold medalist, and former NLM Board chair Tenley Albright M.D., who

had suggested the exhibition topic. The committee included such notable members as Vivien Pinn M.D. (Associate Director for Research on Women's Health, NIH), Senator Barbara Mikulski, Jordan Cohen M.D (President, Association of American Medical Colleges), and Catherine DeAngelis M.D. (Editor, *JAMA*) [22, 50].

Based on the committee's recommendations, "Changing the Face of Medicine" highlighted a very diverse group of women physicians, so young girls could see doctors who "looked like them" and all attendees could learn about the range of careers open to a person with an M.D. degree [51]. Sixty physicians were featured in displays and more than 300 in an interactive multimedia database. At Dr. Albright's suggestion, visitors were invited to "Share Your Story" about other notable women physicians they had encountered. The American Medical Women's Association collaborated with NLM on a companion "Local Legends" website with profiles of outstanding women physicians nominated by their state's Congressional delegation. Dr. Albright, in a white coat, cut the red ribbon with a scalpel to open the exhibition. Many women featured were there with family and friends.

Dr. Lindberg also actively supported increased outreach for the exhibition program through the development of traveling and online exhibitions. For example, NLM developed a version of the "Frankenstein" exhibition that traveled around the United States under the auspices of the American Library Association [22,52]. This project was the first of many traveling exhibitions. The NIH Office of Research on Women's Health helped sponsor the traveling version of "Changing the Face of Medicine" with its intent to interest girls in medical careers. Many other NLM historical exhibitions also aim to interest students in careers in science, medicine, and information transfer.

Although some traveling exhibitions are based on major exhibitions, most are based on smaller exhibitions developed by NLM and involve roll up displays. The Library makes these displays available free of charge to libraries and other cultural institutions, where they are augmented with local materials and programming [52-54]. The traveling exhibition program has been extremely successful. For instance, in the 2012 fiscal year HMD traveled 25 copies of 12 exhibitions to 156 host venues in 43 states and five international locations [35,p.15].

Dr. Lindberg encouraged the development of online versions of exhibitions to further extend the program's outreach. At the time of this essay's preparation, there were more than 35 exhibitions on NLM's website. Dr. Lindberg also fostered the cooperation between the Library other institutions in the preparation of exhibitions, such as the National Museum of American History, the Folger Shakespeare Library, and Mount Vernon [22, 55-57].

In tribute to Dr. Lindberg's vision with respect to the exhibition Program, HMD Chief Jeffrey Reznick Ph.D. wrote in 2015:

"Perhaps the greatest testimony to Dr. Lindberg's sense of the public value of the Library and its collections is the success of the NLM's award-winning Exhibition Program. Over the last fifteen years, the program has touched millions of individuals through its interactive exhibitions and special displays onsite and on the Web, through its online multidisciplinary K-12 and higher education resources, and most of all, though its traveling exhibitions that tour the world and in so doing inform a wide and diverse audience about stories of the past and their relevance to the present and the future" [58].

5. Conclusion

This essay has provided an overview of the most important contributions made by Dr. Lindberg to NLM's historical collections and programs. His appreciation for the value of history and its artifacts is reflected in his words in the foreword to the *Hidden Treasure: The National Library of Medicine*:

"Lastly I take pleasure in echoing the enthusiasm for true, original, real books within our grasp…there are times, especially when we ask why or how a discovery or a belief arose - when we need to see and hold original intellectual works" [59].

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Dr. Lindberg and Scholarly Publishing

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Abstract. Donald A.B. Lindberg M.D., Director of the U.S. National Library of Medicine (NLM) from August 1984-March 2015, had a remarkable vision for NLM's scope, goals, and function. This vision resulted in many external partnerships and initiatives with the publishing industry, commercial and non-profit, journal editors, and professional organizations. These partnerships ranged from ongoing collaboration and dialogue, such as the NLM Publisher's Committee and the International Committee of Medical Journal Editors (ICMJE). to the more practical, such as the creation of HINARI and the Emergency Access Initiative (EAI). Dr. Lindberg fostered partnerships outside the NLM to expand the use and reach of Library resources, including MEDLINE and ClinicalTrials.gov to support innovations in the processes that build them, and improve the quality of biomedical journals. Dr. Lindberg also encouraged the use of technology to enhance medical information and supported the early development of fully interactive publications. Attitudes that contained a measure of skepticism and distrust faded as collaborators came to have a better understanding of both NLM and their partners. This chapter discusses these relationships and accomplishments that NLM achieved working with publishers and other creators and disseminators of medical information under Dr. Lindberg's leadership.

Keywords: Donald A.B. Lindberg M.D., U.S. National Library of Medicine, MEDLINE, Scholarly Communication, Publishing, ClinicalTrials.gov

1. Introduction

Donald A.B. Dr. Lindberg M.D., Director of the U.S. National Library of Medicine (NLM) from August 1984-March 2015, had a remarkable vision for the NLM: its scope, goals, and function. One of his gifts was the ability to see beyond his own four walls, his own perspective, and continually take a broad view of how medical knowledge could impact human health on a global scale. He understood innately the power of partnerships, even among entities whose agendas might appear to be competing, as a means to an end. This chapter discusses these relationships and accomplishments that NLM achieved working with publishers and other creators and disseminators of medical information under Dr. Lindberg's leadership.

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1.1. The Literature Selection Technical Review Committee

When he arrived at NLM, Dr. Lindberg learned that decisions *not* to index some journals for MEDLINE were a common topic of written complaints from editors and publishers, often forwarded by their U.S. Representatives and Senators. As the number of medical journals continued to grow, and as the use of the MEDLINE database to identify relevant articles increased, the scope of the journals indexed by NLM was of increasing concern to NLM, journal publishers, editors, journal article authors, and readers.

In 1984, NLM based its selection decisions on advice from a group of distinguished external consultants with little turnover. Dr. Lindberg did not fault the consultants' qualifications or recommendations, but he concluded NLM needed a more defensible process. In his clear-eyed view, deciding which journals to index was analogous to deciding which grant applications to fund. He thought it should be supported by an official advisory committee established through U.S. National Institutes of Health (NIH) procedures for grant review committees, in accordance with the Federal Advisory Committee Act.

At Dr. Lindberg's request, questions of indexing scope and the appropriate approach to selecting journals to index were considered by NLM and presented to the Board of Regents at its May 1987 meeting [1]. At that point, NLM received about 13,500 journals and indexed more than 3,300 of them for MEDLINE. More than half of the titles received were indexed by one or more of the 14 major scientific abstracting and indexing services at the time. Since the 1960s, NLM and outside experts had used criteria designed to quantify the scholarly quality and importance of the journals when considering which titles should be indexed. Meanwhile, publishers and editors were interested in having their journals indexed. Readers were interested, it was pointed out, that MEDLINE include quality articles relevant to them but exclude those not relevant. Given the variety of users and journals, this was a complex challenge. At NLM, the monthly *Index Medicus* had reached its maximum size for publication in one volume, and MEDLINE needed to be segmented into different files because of software limitations.

Stemming from these discussions, which included consideration of the future development of MEDLINE and other NLM databases, the Literature Selection Technical Review Committee (LSTRC) was formally established as a NIH chartered Federal Advisory Committee in 1988 to review journals for inclusion in *Index Medicus* and MEDLINE - and to advise NLM on journal-related issues. It took time and energy to convince NIH of the wisdom of using a Federal Advisory Committee for this purpose, but LSTRC has remained in place since 1988, surviving periodic efforts to reduce the number of NIH Advisory Committees.

The acronym and full committee name were intentional as Dr. Lindberg hoped it would sound so off putting that it would arouse little interest from government bureaucrats and, consequently, limited controversy. Meetings are announced in the Federal Register and meeting minutes are available, including the list of journals approved for indexing by NLM following the meetings. LSTRC is part of a transparent process of submitting a journal for coverage in MEDLINE that includes screening of the initial application and a check of technical and indexing requirements.

The results of LSTRC meetings were of considerable interest to publishers for many reasons, chief among them commercial, as inclusion in MEDLINE could increase manuscript submissions and greatly improve a journal's citation and impact factor. The latter interests were a precipitating factor in establishing periodic meetings between publishers and NLM staff that are discussed below.

1.2. NLM Publishers Committee and Seminar Collaboration

In 1999, the American Medical Publishers Association (AMPA), a trade organization made up of medical and health sciences publishers, had questions about the NLM related to MEDLINE and the process to select and index in MEDLINE. Jack Farrell, AMPA President, approached Sheldon Kotzin, then NLM's Executive Secretary of the LSTRC, to inquire about MEDLINE and explore ways in which publishers might be able to collaborate with NLM to understand and support the review process. Although AMPA was a relatively boutique organization made up of primarily health sciences book publishers, Farrell was astute enough to engage the new head of the larger Association of American Publishers (AAP) and its new director, former U.S. Congresswoman Patricia Schroeder, as part of this endeavor. Under the banner of the NLM Medical Publishers Committee, the group initiated quarterly meetings with Dr. Lindberg and NLM staff, the first occurred in February 2000.

The Publishers Committee meetings regularly included reporting on decisions made by NLM after LSTRC meetings and discussions of trends in coverage. Through the panel, NLM came to have an increased understanding of the issues facing publishers as they established new journals, and publishers gained in their understanding of the complexities of relevant processes within NLM. The latter contributed to a shift towards more collaboration between NLM and the publishing community, which advanced one of Dr. Lindberg's stated goals.

Another ground-breaking result of this collaboration was the creation of joint seminars by the NLM and the Professional and Scholarly Publishing (PSP) division of the AAP. These day-long events were held in conjunction with the annual PSP meetings in Washington, D.C. and focused on shared challenges. The initial conference, focused on Archiving, was sold out with diverse attendees including NLM employees, publishing staff, vendors and service providers, as well as librarians.

"From the start, Dr. Lindberg understood what we were trying to do,' said Farrell. "We wanted to improve communication between the NLM and publishers and he fully jumped on board." Prior to these conversations, the relationship had been somewhat antagonistic, and was exacerbated by the central role of NLM's National Center for Biotechnology Information in establishing PubMed Central on behalf of NLM. Dr. Lindberg's leadership and understanding of the larger common goals of the two groups led to decades of productive collaboration. He frequently described the partnership using another of his nautical metaphors as "Clear sailing with everyone pulling in the right direction."

When the authors of this chapter undertook to organize the various topics they would cover, they debated a chronological approach versus a type of project approach. Either would bring out interesting aspects of the projects, but in the end it was felt that a roughly chronological approach would better demonstrate an important feature of the efforts, that is the growing spirit of collaboration that developed as all sat around the table in the NLM Board room and spoke frankly of their challenges and aspirations.

2. Permanent Paper

"The use of acid-free paper is the preventive medicine for reducing the problem of deterioration of publications and the threat of their being lost to the record of civilization forever, said Charles Kalina, NLM Special Projects Officer [2].

NLM has a fundamental responsibility to preserve the content of books, journals and other library materials in its collection scope. At the same time, a major threat to the survival of books and journals published since the mid-nineteenth century has been the deterioration of paper caused by residual acids it contains. In 1984, just prior to Dr. Dr. Lindberg's arrival, NLM's Library Operations Division launched a comprehensive trans-NLM preservation study which produced a 1985 plan for ensuring the preservation of the NLM collection. A survey of the physical state of the collection undertaken as part of the study identified more than 12 percent of the collection was too brittle to withstand even one more library use. This was significantly less than had been found in surveys of collections other research libraries, but it was destined to expand.

Recommendations for addressing this problem included microfilming deteriorating documents, conservation of rare and variable materials, continuing research into digitization and electronic storage which were not yet feasible as preservation mechanisms and mounting a campaign to encourage future publication on archival materials, e.g., acid-free or permanent paper for print publications [3].

Dr. Lindberg supported progress on all these fronts, but he focused on the "permanent paper campaign," where his personal involvement was likely to be important to success. At the same time some were skeptical that NLM could influence publishing practices, but reducing future problems appealed to Dr. Lindberg. The permanent paper campaign also presented a golden opportunity for positive collaboration with publishers.

The NLM Board of Regents was briefed on the preservation plan in late 1985 and approved a revised preservation policy in 1986 which stated: "NLM shall actively encourage the publishing industry to use more durable materials in the production of the biomedical literature."

Dr. Lindberg quickly recruited Charles Kalina to become NLM's resident expert on paper composition, production, and supply issues and provide key support for the campaign. Following a Board of Regents hearing on permanent paper at NLM in January 1987, with U.S. Congressmen William Natcher as keynote speaker, the Board established a Permanent Paper Task Force representing all stakeholders. Task Force Members and NLM staff members undertook a number of efforts, including individual contacts with editors and publishers of journals indexed in MEDLINE, to encourage more use of acid-free paper. Fortunately acid-free paper was becoming more available and economical at the time.

By 1991, considerable progress had been made: 80 percent of the U.S. journals indexed by NLM were acid-free [2]. In addition to emphasizing use of acid-free paper in biomedical journals, NLM played an important role in advancing its use in U.S. government publications. Progress would continue to be made over the years, aided in part by standards development and continuing conversations with stakeholders, including publishers.

3. Errata, Retractions, and other Linked Citations

"Fraud in scientific research is unacceptable and inevitable." [4].

Academic and research organizations, government and other agencies sponsoring research, individual publishers, authors and readers all have a vested interest in assuring the accuracy of the published literature. In the early 1980s, there were some celebrated cases of published articles that were subsequently repudiated due to evidence of scientific fraud.

Effective in 1984, just prior to Dr. Lindberg's arrival, NLM began to index retractions of articles published in the journals covered by MEDLINE and connect them to the MEDLINE citations for the original articles. In 1986, the U.S. National Institutes of Health (NIH) and various universities developed procedures to address research misconduct, defined as: fabrication, falsification, and plagiarism. In 1988, the International Committee of Medical Journal Editors (ICMJE) issued a statement about when and how to issue retractions, including NLM-recommended specifications, e.g., a complete reference to the article being retracted [5]. Dr. Lindberg admired NLM's leadership in this area and approved its expansion.

Dr. Lindberg often spoke of the vital role NLM indexers played in contacting publishers about serious errors, e.g., dosage, in abstracts and in alerting users to articles with subsequently published errata or retractions. By placing such information in MEDLINE and creating links between the relevant citations, NLM also made readers aware of corrected articles, duplicate publications, article updates, expressions of concern, comments, patient summaries, and republished articles. In this way, the reader is alerted to other information relevant to an original article [6]. These communications and the policies supporting them were facilitated by NLM's role as a member of the ICMJE and the long-standing cooperation of its members.

4. The International Committee of Medical Journal Editors (formerly the Vancouver Group) and the Expansion of ClinicalTrials.gov

The ICMJE was founded as a collaboration of influential medical journals with a mission to standardize editorial guidelines for submissions to biomedical journals.

This elite group initially met in Vancouver, BC, and in 1979 issued the first version of the *Uniform Requirements for Manuscripts Submitted to Biomedical Journals*. The group had asked NLM to specify the required format for bibliographic references and invited NLM's Executive Editor of *Index Medicus*/MEDLINE to join the Committee, which established an enduring association between the two entities. The current ICMJE requirements, now called *Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals*, reflected a scope that goes far beyond manuscript preparation, by veteran and new journal editors alike. As mentioned previously, ICMJE statements about retractions and errors supported NLM's efforts to index and highlight them.

Another important collaboration between NLM and ICJME involved ClinicalTrials.gov. In February 2000, NLM launched ClinicalTrials.gov in response to the U.S. Food and Drug Administration Modernization Act (FDAMA) of 1997. FDAMA required the NIH to create a public information resource on certain clinical trials regulated by the U.S. Food and Drug Administration (FDA). In a communication to Dr. Lindberg on September 1, 1998, NIH Director Harold Varmus asked NLM to assume responsibility for building the system, citing the Library's "rich experience in managing the AIDS CTIS [clinical trials information system] and its depth in information technology" [7]. FDAMA's intention was to give patients and their physicians better access to information about open clinical trials for serious and life-threatening conditions. The law required the registration of such trials if regulated by FDA, but it had no enforcement provisions.

In the early 2000s, some highly publicized papers published in ICMJE member journals were subsequently shown to have reported drug trial results selectively, which

omitted the full disclosure of significant side effects in some patient groups. Registration at the outset of trial began to be viewed as a key initial step toward clinical trial transparency and meeting obligations to research participants. Registration reveals the existence of trials and their key pre-specified characteristics, enabling some assessment of the completeness of later reported evidence.

Angry their journals had been used to deceive, ICMJE members issued a policy statement in September 2004 requiring complete registration of a clinical trial in a "qualified registry" prior to admitting the first patient - as a pre-condition for subsequent publication of the trial's results in their journals [8]. This requirement applied to trials initiated on July 1, 2005 or later. The deadline for registering trials active on July 1, but not yet registered, was September 13, 2005.

The published ICMJE statement named ClinicalTrials.gov as the sole qualified registry then available, although it indicated other qualifying registries were on the horizon. In fact, ClinicalTrials.gov did not meet the ICMJE criterion of being open to all prospective registrants because registration was limited to trials with a U.S. location.

In response to the ICMJE action, Dr. Lindberg quickly made a decision to lift this limitation, which permitted the submission of trials without a U.S. location. He believed a global increase in trial registrations would make the database more valuable to the public, journal editors, and those engaged in systematic review of evidence.

Dr. Lindberg also understood the power of journal editors to compel the submission of research data, based on previous experience with sequence deposits in GenBank. As Dr. Lindberg anticipated, the ICMJE policy sharply increased the number of trials registered in ClinicalTrials.gov and the number of different organizations in the U.S. and elsewhere, who submitted registrations [9]. The ICMJE followed up its registration policy by providing helpful guidance about including trial registry numbers in articles about trials, facilitating links between PubMed and ClinicalTrials.gov. The Committee also clarified that submission of summary trial results to ClinicalTrials.gov and other registries did not constitute prior publication.

By design, the ICMJE was and remains a decentralized and non-bureaucratic organization. Membership is by appointment only, and the group has no officers or budget. NLM staff were active contributors to many ICMJE initiatives during Dr. Lindberg's tenure, although it is important to note that staff participating in the ICMJE initiatives typically were not directly responsible for NLM policy in these areas.

Dr. Lindberg encouraged the ICMJE to take a global and diverse view of medical information. Several ICMJE members have participated as mentors in the African Journals Partnership Program (AJPP), established in 2004 with funding from NLM and the NIH Fogarty International Center [10]. In 2013, the *Ethiopian Journal of the Health Sciences*, one of the journals mentored in the AJPP, was invited to join the ICMJE, a testament to Dr. Lindberg's enduring influence. The NLM remains a member of ICMJE.

5. Structured Abstracts

Beginning in 1975, NLM's MEDLINE database included author generated abstracts up to 250 words (400 words for certain cancer-related articles) with its journal article citations.

In 1987, R. Brian Haynes M.D. Ph.D., the noted informaticist and Professor at McMaster University School of Medicine, called for improved abstracts, ones that would represent the content of a paper in a manner more useful to the reader [11]. Most journals

employed the IMRAD flow (Introduction, Methods, Results, and Discussion) but there was no particular structure within abstracts. Haynes sent his proposal to Edward Huth M.D., the editor of *Annals of Internal Medicine* who sought input from the Ad Hoc Working Group for Critical Appraisal of the Medical Literature. Their multinational members were interested in improving the communication of healthcare evidence [12]. Studies published at that time suggested most clinicians did not search the journal literature to solve problems that arose in the course of clinical practice [13].

Dr. Lindberg supported the writing of Structured Abstracts (SAs) as they gave MEDLINE users, including the growing number of individual health professionals searching via NLM's Grateful Med interface, bold category headings and greater detail on study design, selection and number of participants, interventions, outcome measures, key findings, and clinical applications. Not only were these abstracts better organized but they provided more substantive information, resulting in more access points for MEDLINE users. Harbourt and others explored the utility of the SAs in citation retrieval [14]. They noted that Dr. Lindberg waived the MEDLINE limit of 250 words per abstract, allowing full SAs regardless of length. Analysis suggested that articles with SAs contained an average of three more Medical Subject Headings (MeSH) terms compared to other abstracts for MEDLINE articles. So, the additional access points were likely to assist in bibliographic retrieval. As a result, Dr. Lindberg's decision to include entire SAs regardless of length contributed to publisher decisions to comply with and leverage this structure.

In 2010, Dr. Lindberg invited Brian Haynes to discuss SAs with NLM staff. By this date, SAs were used by many publishers and were widely accepted by MEDLINE users. NLM staff had taken steps that improved the display of SAs in citation retrieval. Also, the ICMJE recommendations endorsed their use in publications. The SA discussion with Haynes centered on NLM conducting more research, enhancing MEDLINE citation display, improving retrieval in MEDLINE/PubMed, and supporting use of SAs in published papers.

These efforts were successful and helped clinicians more efficiently identify articles most relevant to their clinical needs, a recurring theme for Dr. Lindberg.

6. Clinical Alerts

In some cases, early pre-publication clinical research results justify stopping a clinical trial and making immediate changes in clinical practice. Aware of the importance of getting such results out to the practitioner community in a way that did not jeopardize their later journal publication, NIH held a meeting in January 1991 to discuss how to alert the community of dramatic results of a clinical trial and to hear from journal editors about their concerns.

At the meeting, Dr. Lindberg offered NLM's assistance in disseminating such alerts using the MEDLARS system and the National Network of Libraries of Medicine (NN/LM). Coincidentally, two days after the NIH meeting, the U.S. National Institute of Child Health and Human Development requested assistance to distribute a clinical alert on pediatric AIDS to supplement its own press conference and direct mailing of an announcement. The first Clinical Alert was distributed on MEDLARS within 24 hours and also faxed to the 135 resource libraries in the NN/LM and mailed to all Network member libraries [15]. NLM worked with member libraries to encourage redistribution of the Clinical Alerts within their institutions.

Clinical Advisories provided by NIH Institutes were later added to NLM's distribution system. While the means of distribution changed over the years, Clinical Alerts and Clinical Advisories continued to be distributed by NLM into 2014, after which NIH Institutes took responsibility for alerting users directly via their websites.

7. Out of Crisis, Opportunity: Transitioning to Publisher-supplied MEDLINE Citations and Abstracts

In the mid-1990s, MEDLINE was evolving as the speed of innovation and research was driving exponential expansion in the number of journals and papers published. A major part of the MEDLINE process was capturing in machine readable form the citation and abstract for each article selected for indexing. The majority of this machine-readable data was created for NLM via a contract with a third-party keyboarding firm.

In 1996, a protest by one of the firms vying for the keyboarding contract caused a stoppage in the work and data loading into MEDLINE, resulting in a significant backlog and few new citations being added to one of world's most invaluable databases. While the protest was being adjudicated, NLM was forbidden to purchase any interim outside assistance. NLM's staff scrambled to address the backlog, keying some data themselves, developing a scanning/optical character recognition (OCR) input stream, and requesting machine-readable data from publishers.

While the dispute with the contractor was resolved in NLM's favor, the experience caused Dr. Lindberg to reach two conclusions. First, the precision and skill of the keyboard contractors, even though performing relatively routine and low paid work, was not trivial. Second, he was determined to use technology and cooperation from the publishers to eliminate the dependency on keyboarding in the MEDLINE production process. Dr. Lindberg told the Board of Regents at a May 1996 meeting that while the input crisis was significant, MEDLINE and MEDLINE processes would emerge "smarter and stronger" [16].

Dr. Lindberg assigned lead responsibility for developing an OCR input stream to George Thoma Ph.D., Chief, Communication Engineering Branch in NLM's Lister Hill National Center for Biomedical Communications, and asked David Lipman M.D., Director of NLM's National Center for Biotechnology (NCBI), to work aggressively with publishers to submit machine readable data for their journals' citations and abstracts. While NLM had been working for a decade to set up a machine-readable input stream from publishers, the interruption of the keyboarding stream gave publishers a much stronger incentive to participate.

In 1996, Dr. Lindberg set an initial goal of obtaining machine-readable data for one third of citations and abstracts from each of three methods: scanning/OCR, electronic submissions from publishers, and double keyboarding. His goal was achieved in 1999.

By mid--2004, NLM was able to cancel the keyboarding input stream. By that time publishers were delivering 74 percent of citations and abstracts in electronic form. An unintended but very real consequence of the expansion in production bandwidth and reduction in input costs was the ability to expand MEDLINE to include more journal titles, including journals in subject areas such as physics, climate science, and engineering. This allowed MEDLINE to mirror shifts in research and the growing overlap in scientific disciplines. This expansion of MEDLINE's scope benefited publishers of all shapes and sizes.

8. Efficiencies in Indexing

A large-scale activity within NLM's Library Operations over the years has been the description of articles from high quality medical journals to facilitate their retrieval. This indexing is a 150-year-old tradition and includes adding descriptive and subject data not supplied by the publisher when articles are submitted. Originally indexing was done exclusively by library staff and contractors, but as the volume of both indexing activity and information retrieval research grew, the Library began to explore the use of natural language processing in tandem with human efforts. Early initiatives in this arena led to the creation of a cross-library indexing initiative by Dr. Lindberg in 1996. This was of interest to journal publishers and the extended biomedical research community, as it provided opportunities to improve the quality and timeliness of indexing operations, while reducing costs [17].

The resulting system, the Medical Text Indexer (MTI), has provided automated indexing recommendations since 2002. It makes use of publisher supplied material, related citations, and the MeSH vocabulary via The Unified Medical Language System (UMLS) in a process resulting in an ordered list of recommendations of MeSH descriptors, supplementary concepts (mostly chemicals), and publication types available to indexers. Since 2011, it has been used without human indexing, but with the standard manual review process for a growing number of journals found to be amenable to this approach [18]. Ongoing statistics are kept on use of MTI and techniques for further refinement are addressed on an ongoing basis. Recently, NLM announced the MEDLINE2022 initiative, with the goal of fully automated indexing by April 2022.

9. HINARI

A World Health Organization (WHO) effort that began in the 1990's with concerns about WHO libraries getting online access to Elsevier journals expanded into a larger consideration about how publishers might support researchers in developing countries. This resulted in a partnership with publishers that created the Health InterNetwork Access to Research Initiative (HINARI). The framework of the Health InterNetwork in which HINARI was developed was introduced by the United Nations' Secretary General Kofi Annan at the UN Millennium Summit in 2000.

The framework's principles included multilateral and multi-sectoral partnership, a commitment to equitable price, transparent criteria for inclusion, respect for copyright, a common license agreement, a one-stop delivery mechanism, initial commitment by publisher partners to a minimum of 3-5 years, and integration with WHO global development efforts and the wider socio-economic context [19].

The development of HINARI was regularly discussed at the NLM Medical Publisher's Committee and Dr. Lindberg offered the assistance of the NLM PubMed staff in addressing the technical linkage challenges, using the PubMed LinkOut feature to make existence of HINARI full-text resources visible to qualified PubMed users. WHO played an administrative role, identifying eligible institutions, housing and maintaining the HINARI server and central functions. The BMJ group, a publishing partner, provided a staff member, which led in the development of a common license agreement. Yale University Library provided technical assistance and worked on training, Publishers were full partners in developing the framework, providing journals, and monitoring results.

HINARI went live in 2002, offering content from 1500 journal titles from five publishers to qualifying health sector institutions in developing countries with the lowest GNP per capita, without charge. Publishers and journals were added over time, and provision was made for providing access to a second tier of qualifying institutions at significantly reduced prices. Currently, about 21,000 journals, 6,900 e-books and 115 other information resources are available to health institutions in more than 125 countries, areas and territories. The service benefits many thousands of health workers and researchers, and in turn, contributes to improving global health. The success of HINARI also led to the development of similar efforts covering research in agriculture, the environment, development and innovation and global justice, with the five dimensions collectively identified as Research4Life [20].

10. The Emergency Access Initiative

In addition to his long-term vision for the NLM, Dr. Lindberg never lost his ability to focus on practical solutions to short-term challenges. This pragmatic approach is evidenced by the creation and implementation of the Emergency Access Initiative (EAI).

In 2005, regions within the United States were devastated by Hurricanes Katrina and Rita. The humanitarian crisis these natural disasters created prompted significant response from both health care workers and health sciences libraries.

Individual libraries in the United States and elsewhere struggled to provide relief workers with health information resources and services, but first responders universally pointed to the need for a single strategy to deliver potentially life-saving treatment information. Leveraging the existing collaboration between the NLM and the Professional and Scholarly Division of the Association of American Publishers, the Emergency Access Initiative (EAI) was created to provide free, full-text access to the clinical information most needed by health care professionals and librarians responding to a disaster - and to serve as a temporary replacement for library collections rendered inaccessible by disaster. The EAI leveraged the partnership between the NLM and the Medical Publishers Committee to secure access to clinical content, primarily through eBooks and eBook databases. With the support of publishers, this coverage quickly expanded to include leading journals.

Conceived by the NLM as a resource to be used in a domestic disaster, the EAI was first deployed to respond to an international crisis on January 25, 2010, 13 days after a catastrophic earthquake struck the Caribbean Island nation of Haiti. The initial EAI activation period of one month was extended by an additional four weeks through March 19, 2010. During the two-month period, 2,835 visitors accessed the site, 554 more than once, for a total of 4,743 visits, and 88,473 page views.

The EAI has been activated multiple times since its inception. In addition to Haiti, the EAI has supported frontline workers responding to multiple international disasters, including flooding in Pakistan (2010); the cholera epidemic in Haiti (2011); an earthquake & tsunami in Japan (2011); a typhoon in the Philippines (2013); an Ebola outbreak in West Africa (2014); an earthquake in Nepal (2015); hurricane Maria in Puerto Rico (2017); and hurricanes Harvey and Irma in the U.S. (2017).

The EAI embodies many of Dr. Lindberg's core principles, so much so that in his retirement address he cited EAI within a list of personal favorite NLM programs that were created during his directorship.

11. Interactive Publications

Always attentive to the possibilities of new technologies and new uses of them, Dr. Lindberg and the NLM Publishers Panel held a number of discussions about interactive publication in the mid 2000's.

Dr. Lindberg understood the value of heart sounds in cardiology journals or moving images of gait and balance in interactive neurology journals. He recognized that a visualization of a scientific experiment had benefits compared to a verbal description. While it was estimated that interactive publications, with material manipulable by the reader, accounted for only two percent of the published basic science and clinical journal articles indexed by NLM in 2007, it was anticipated that this number would grow significantly [21]. The growth of interactive publications was seen as a challenge to both the publishing community and to NLM, although it could boost the potential for journal article readers to benefit from enhanced learning and understanding.

NLM undertook three complementary initiatives to provide platforms and tools for experimenting with interactive technologies and assess their impact on users [22]. One of these was an experiment carried out in collaboration with Elsevier and the Student National Medical Association (SNMA). The experiment included two stages. In the first, a group of medical students reviewed 12 articles published in three Elsevier medical journals and suggested desired enhancements to improve learning, enhancements that were then incorporated in one article if possible. The second stage involved experimental and control groups who viewed the original and modified article and were tested on their knowledge gain. While the experimental group took somewhat longer to complete the activities, their results showed comparatively statistically significant knowledge gains and acceptance of the experience.

In a related effort, NLM created a visualization and analysis tool called Panorama and submitted it to the Elsevier Grand Challenge contest conducted in 2008-9, which invited researchers to "prototype tools dealing with the ever-increasing amount of online life sciences information" [23]. The NLM submission was judged a semi-finalist. Despite recent efforts to include ancillary material and original data with research articles, publisher innovation in this area remains relatively insignificant.

12. Conclusion

Dr. Lindberg envisioned a world in which medical information could improve the life of all humanity. This vision impacted his leadership within the NLM and inspired many fruitful partnerships outside the Library. Dr. Lindberg's pragmatic and humble approach led to many projects and initiatives that live in the fabric of healthcare information in the U.S. and around the world.

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Promoting New and Expanded Roles for Librarians and Information Specialists

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Abstract. This chapter describes how the U.S. National Library of Medicine (NLM), under the leadership of Donald A. B. Lindberg M.D., promoted new and expanded roles for librarians and information specialists in response to advances in technology and public policy. These advances brought information services directly to all potential users, including health professionals and the public and stimulated NLM to expand its programs, policies, and services to serve all. Dr. Lindberg included librarians and information specialists in all of NLM's new endeavors, helping both to recognize and establish new or expanded roles. The involvement of librarians and information specialists in multidisciplinary healthcare research teams, in underserved communities, and in research data management and compliance has helped to redefine the health sciences information profession for the 21st century.

Keywords: Donald A.B. Lindberg M.D., U.S. National Library of Medicine, Librarians, Access to Information

1. Introduction

The work of health sciences librarians and information specialists changed substantially in the two decades before Donald A.B. Lindberg M.D. arrived as Director of the U.S. National Library of Medicine (NLM) in 1984. Major change agents included: implementation of the Regional Medical Library (RML) Network and NLM grant programs; great expansion in the number of medical libraries and the size of collections; the advent of MEDLINE (1971) and other online databases; development of shared bibliographic utilities and serial holdings databases; and automated support for internal library operations [1]. These and other developments required many librarians to acquire new knowledge and skills, including expertise in online searching. Demand for online searches and document delivery exploded. Time required for acquisitions and cataloging declined. New opportunities for librarians in education, research, and resource and service development emerged.

Some notable results included: the first clinical medical librarian programs; the concept of Integrated Academic Information Management Systems (IAIMS); and early systems enabling individual health professionals and students to search MEDLINE subsets in some medical schools and teaching hospitals [2-5].

The developments from 1965 to 1984 transformed how many health sciences librarians and information specialists performed their work, but had less effect on the health professionals, researchers, students, and, in some cases, the patients they served.

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In 1984, however, significant changes in the technology affordable to users, in the expansion of electronic information sources, and in user expectations were on the near horizon. These changes would have an even greater impact on the roles librarians and information specialists performed.

I first became of aware of Don Lindberg in 1984 when he was appointed Director of NLM and I was working as a librarian for the American Medical Association (AMA). Don's appointment was very disappointing to some in the medical library community because we hoped a librarian would be appointed to the position. We did not realize that his groundbreaking achievements in medical informatics, his experience as professor and chair of the Department of Information Science at the University of Missouri-Columbia's School of Library and Information Science, his role as an advisor to the IAIMS study, and his high regard for librarians' expertise would prove to be key to the expansion and evolution of the medical library profession into what it is today.

Don arrived at NLM at the point when personal computers made it technically feasible, but not yet easy, for individual health professionals to access MEDLINE and other NLM databases from offices and homes. He envisioned a future in which biomedical knowledge would be directly accessible from electronic health records (EHRs) for the benefit of health professionals and patients. He believed NLM could and should hasten the day when biomedical knowledge and data were readily available to health professionals, biomedical researchers, students, and patients – when and where they needed it. As quickly became clear to those who had direct contact with him, Don expected librarians and information specialists to be part of the multidisciplinary workforce needed to make this future a reality. He also expected librarians to have expanded responsibilities and stature within this future.

Don included librarians as key participants, and often leaders, in all of the major projects he initiated at NLM. In a planning process he also initiated, the NLM Board of Regents appointed many external librarians to the purposefully multidisciplinary panels convened to develop the 1986-2006 NLM Long Range Plan and all subsequent NLM planning documents [6]. For planning, Don believed "you should start out with the people you're trying to serve and find out from them what would actually help and what's possible," a philosophy that changed the programs, products, and services of NLM and strongly influenced the roles that health sciences librarians assumed in the ensuing decades [7,p.21]. Throughout Don's tenure, NLM's plans consistently addressed the need to prepare librarians for important contributions in the changing biomedical and health environment [8].

Under Don's leadership, NLM supported new and expanded roles for librarians and information specialists in many ways. NLM's influence on the expansion of education and training opportunities for librarians is summarized by Holst [9]. In contrast, this chapter highlights: the intertwined impacts of advances in technology and public policy; the re-orientation of the Regional Medical Library (RML) Network to reach individual health professionals and the public; the expansion of NLM programs, products, and services; and the expansion of librarians' research roles.

2. Bringing Information Services to Users and Potential Users

Upon arriving at NLM, Don took immediate steps to develop an inexpensive user-friendly interface to MEDLINE to encourage searching from the increasing numbers of personal computers in physicians' offices and homes [10]. Less than two years later, in

February 1986, NLM's Grateful Med software package joined the emerging array of systems aimed at physicians without specialized search training. Aided by the recently established Friends of the National Library of Medicine (FNLM), NLM began an active campaign to publicize Grateful Med directly to health professionals, as well as to librarians in the RML network. Soon thereafter, Congress encouraged NLM "to develop an outreach program aimed at ...[the] transfer of the latest scientific findings to all health professionals... in rural communities and other areas .... NLM's mission was explicitly amended to add the function to "Publicize the availability of[its] products and services... " [11].

Responding to Congress, the NLM Board of Regents convened a distinguished multidisciplinary outreach planning panel in 1988, chaired by Michael E. DeBakey M.D. The Panel's 1989 report, *Improving Health Professionals Access to Information,* found the majority of health professionals were unaffiliated with a library. In addition to advocating for increased support for connecting hospitals to the Internet and expansion of medical informatics training and IAIMS grants, the report encouraged NLM to refocus the RML Network on outreach to individual health professionals, especially underserved health professionals, to help them access national biomedical information sources. "To do this, the RMLs should act as a "field force" for NLM products and services, providing information and services to health professionals directly and through network libraries" [12]. Dr. DeBakey and the report were influential in obtaining additional Congressional funding for the renamed National Network of Libraries of Medicine (NN/LM).

As Humphreys noted in a lecture on historic relationships between NLM and health sciences librarians at the 2001 annual meeting of the Medical Library Association (MLA), "the greatest friction…occurs when there is a fundamental change in the way NLM carries out its mission…" [13]. And Don did promote change, especially in the area of providing medical and health information to all through the creative use of existing technologies.

The promotion of Grateful Med by NLM to the healthcare community at large and the use of network librarians as a "field force" to encourage unaffiliated health professionals to use it resulted in a display of this "friction" in an infamous standing room only debate between Don and Herb White, professor of library science at Indiana University-Bloomington, at the May 1992 MLA Annual Meeting (which, coincidentally, was my first Annual Meeting as MLA Executive Director). Many librarians in academic institutions and teaching hospitals already had their hands full teaching online searching and providing user-friendly search interfaces, including Grateful Med, for their own faculty, staff, and students. Other librarians, especially in hospitals, were fearful their jobs would be cut if administrators thought that health professionals could locate information on their own.

In Don's view the "role of the health sciences librarian in the 1990's is to be recognized…as an authority on access to information related to the biosciences" [14,p.72]. He also referred to MLA's educational policy statement, "Platform for Change," focusing on the individual's responsibility for lifelong learning. This would be crucial in encouraging health sciences librarians to learn new roles as the technology continued to evolve throughout the coming decades. White countered that NLM's "databases cannot be properly used without enough medical library intermediaries" and Grateful Med is only one source of medical information [15].

However, history demonstrates that Don's broader perspective prevailed. Direct access to electronic information sources by health professionals was inevitable and

valuable; systematic reviews and other complex searches for evidence required trained search experts.

The NN/LM personified Don's concept of a "network" providing "training on NLM information resources, funding of local and regional projects, and coordination of medical library services" [6]. Although resisted by some, the initial Grateful Med outreach projects (1990-92) encouraged some librarians to take on the role of teaching underserved health professionals not affiliated with their institutions and helping them to connect to library services. They provided useful lessons learned for the many subsequent NN/LM supported outreach efforts [10].

Meanwhile, access to the Internet was increasing, and NLM had begun to fund Internet connections for hospitals. Soon after the Lindberg-White debate in 1992, NLM organized, and MLA co-sponsored a satellite broadcast entitled "Information STAT! Rx for Hospital Quality" stressing the importance of hospitals' connecting to the Internet and the value of libraries and librarians in improving hospital quality and cost effectiveness [16]. The program featured hospital librarians, physicians, and other health professionals, with videos of existing advanced services and outreach programs. It provided a good picture of the power of hospital library services in combination with Internet connections.

By the end of 1990, a basic World Wide Web system had been launched. In 1993, the first Web browser demonstrated its value for the general population - and as a universal interface for information service providers. By 1997, the spread of the Internet and Web-capable workstations enabled NLM to provide free access to MEDLINE worldwide via PubMed for anyone with a Web browser. (Previous NLM charges for online searching covered the cost of commercial telecommunications.)

NLM's MedlinePlus.gov consumer health web information service and web interfaces to other NLM information services soon followed. Once NLM online services were free on the Web and directed toward a broader range of users, the NN/LM supported librarians in greatly expanded outreach to, and collaboration with, health professionals, researchers, public health departments, the HIV/AIDS affected community, public libraries, other community-based organizations, as well as the general public [17]. Inexpensive "smart" hand-held devices further expanded the universe of potential users and the range of circumstances, e.g., travel, emergencies, disasters, in which information was accessible.

Effective outreach involves listening and learning about people's information needs, making them aware of available information sources and access tools, and facilitating their use of these resources. This is now an important and enduring role for health sciences librarians and information specialists. Prior to the 1990s, many librarians were primarily focused on those who came to the library seeking service. Now librarians are out among current users and potential users. Many are embedded with users to better understand and meet their real information needs. Under Don's leadership, NLM and the NN/LM helped to hasten this transition.

3. New and Expanded Information Roles

Any new NLM program, service, or initiative raises the potential for new roles for librarians and information specialists. During Don's 30-year tenure as director, the expansion of NLM's scope was remarkable, e.g., bioinformatics, advanced imaging, consumer health information, clinical trials data, health data standards, disaster

information management, and support for compliance with new requirements for public access to research results and electronic health records (EHRs). Don encouraged NLM staff to seek help from health sciences librarians whenever it embarked on any new endeavor. He also encouraged NLM staff to assist, highlight, and applaud librarians as they embarked on new roles. NLM assistance sometimes involved training for specialized roles, e.g., in consumer health and in disaster information, as described by Holst [9]. This chapter provides examples of other ways NLM helped to foster new roles for librarians and information specialists.

3.1. Support for Informationists

The concept of the "informationist' was proposed by Frank Davidoff M.D. and Valerie Florance Ph.D. in 2000 [18]. They characterized these new professionals as knowledge workers formally trained in both clinical sciences and information sciences so they can retrieve, synthesize, and present medical information routinely as members of clinical health care teams. "Informationists" were distinguished from clinical librarians primarily by their training in biomedical as well as information science and their position as specialists embedded within their teams. Not long after the introduction of the concept, informationists were practicing in a variety of settings, including clinical, biomedical research, and public health. The NIH Library, under the direction of Suzanne Grefsheim M.Ed, M.S.L.S. and with the support of John Gallin M.D., Director of the NIH Clinical Center, pioneered the use of informationists in clinical research.

On April 4-5, 2002, a conference organized by MLA to facilitate a national discussion of the informationist concept took place at NLM, which also provided financial support. The librarians and health professionals who participated in the conference concluded:

> The informationist concept meets a critical need for an intermediary between the expanding information universe and practitioners. … Persuading people to become informationists and users of informationists' services will require successful and visible model projects. Training entrants to the role must combine formal educational programs, apprenticeships or mentorships, structured clinical learning experiences, and peer-to-peer teaching [19].

Beginning in 2003, NLM took steps to meet these needs, under the direction of Dr. Valerie Florance, then NLM Associate Director for Extramural Programs. She first established an NLM grant program for budding informationists, the NLM Individual Fellowship for Informationist Training. This fellowship program supported coursework and internships in clinical, biomedical research, public health, and consumer health to prepare Fellows for new career directions. This program concluded in 2008. It was followed in 2010 by Administrative Supplements for Informationist Services, another brainchild of Dr. Florance. Funded by NLM and other NIH institutes, this program provided grants for NIH-funded extramural researchers to immerse informationists in their research teams, often to assist with research data management. These grant programs improved research skills and knowledge about the research community, as well as developing best practices and demonstrating the roles information specialists could play in research data management [20-21].

3.2. Health Information Literacy

NLM recognized health information literacy as a necessity if patients and the public at large were to understand and evaluate the information that Web services and librarians were providing to them. In the 2000s, a health literacy gap among the general population was being reported through a number of studies by The Joint Commission, the American Medical Association, the Agency for Healthcare Research and Quality, the US Department of Education, the Institute of Medicine (now the National Academy of Medicine), and the U.S. Department of Health and Human Services. In one of my periodic meetings with Don and Betsy Humphreys as MLA's Executive Director, they brought up health literacy and health information literacy as challenges which health sciences librarians could help to address.

A search of the NLM's PubMed database in early 2009 showed a 2900% increase in articles about "health literacy" from 1998 through 2008 confirming that this was an increasingly important topic. A study by Shipman, Kurtz-Rossi, and Funk, funded by NLM, surveyed hospital administrators and health care providers about consumer health information and developed a curriculum to be taught by librarians to increase awareness of health literacy issues, encourage the use of NLM consumer resources such as MedlinePlus and Information Rx, and promote the role of librarians as key providers of consumer health information resources and services [22]. Again, support by NLM both financially and by NLM staff, including Elliot Siegel and Rob Logan, was crucial in the study and promotion of this important role of health sciences librarians.

3.3. Electronic Patient Records and Health Sciences Librarians

The 1994 Joint Commission standards for health care organizations integrated the information management function, encompassing patient-specific information, aggregate and comparative patient data, and knowledge-based information (the traditional library collections and services). Although threatening to the status quo for hospital libraries, the functional approach opened potential new roles for hospital librarians, just as the IAIMS concept did for academic health sciences librarians and provided a platform for working with hospital colleagues and vendors on connections between electronic knowledge resources and EHRs as both became more prevalent [23].

In a 2005 perspective speculating about the future of medical libraries in the next decade, Don and Betsy re-envisioned broad deployment of EHRs providing "enhanced opportunities to deliver customized information when and where it is needed." These would include "…remote consultations with information specialists," who as members of the health care team could "tailor summarized evidence to the specific patient," based on data in the EHR [24]. By 2009, Don was particularly interested in the potential of personal health records and their ability to give individuals greater input to and control over their health care and their data. Prompted by him, that year an MLA/NLM Joint Electronic Personal Health Record Task Force was established to explore health sciences librarians' roles in linking patient records to knowledge-based information to support decision-making.

As one outcome, Don and MLA's president co-signed a 2009 letter to personal health record vendors recommending the inclusion in their products of a statement with links to MedlinePlus, MLA information about high quality health information, and pointers for obtaining librarian assistance. A copy of the letter was forwarded to the Joint Commission on the Accreditation of Healthcare Organizations (now The Joint

Commission) [25]. In response, The Joint Commission added stipulations about access to knowledge-based information from EHRs to its accreditation standards, adding another potential responsibility to health sciences librarians' jobs and strengthening their value to their institutions. Such connections were later mandated in EHR requirements issued by the U.S. Department of Health and Human Services (HHS).

3.4. Compliance with Requirements for Public Access to Research Results

The increase in research articles published in MLA's journal in the years following Don's arrival at NLM has been well documented [26-27]. MLA strongly encouraged research in its 1987 strategic plan, which called for "leadership in research in health information science," and NLM's actions during Don's tenure also had a positive effect [28].

Don was a strong advocate of multidisciplinary research teams. During his interviews for the NLM directorship, he asked Lois Ann Colaianni, Associate Director for Library Operations, "what were her expectations, what would she like, and she essentially said she thought that the librarians could do some research. And I said, … if I come here, they're going to get ample opportunity to do research. That I can guarantee you" [7,p.16].

Don quickly made good on that promise by including librarians at NLM, RMLs, and other network libraries in new projects he initiated not long after his arrival, e.g., the Unified Medical Language System, the evaluation of MEDLINE CD-ROM products, and the Critical Incident Technique (CIT) study [29-31]. Don also encouraged NLM's staff to include research-related projects in the experiences offered to participants in the NLM Associate Fellowship Program, a practice which also helped to expand the cadre of librarians participating in research.

Conducting research was not a new role for health sciences librarians, although it started to expand in the late 1980s. In the 2000s and 2010s, in addition to NLM's encouragement of the use of research informationists, new NLM services and related policy developments encouraged the emergence of new roles related to research compliance.

In February 2000 (the joint timing was coincidental), NLM released PubMed Central (PMC), an NIH-initiated free electronic archive of full text articles from biomedical journals, and ClinicalTrials.gov, a free NIH registry of clinical trials of drugs for serious and life-threatening conditions - established in response to a 1997 law. NLM was assigned responsibility for both developments by NIH Director Harold Varmus M.D. In the case of PMC, the goal was to provide an alternative to expensive and restrictive access to online biomedical journals, which was frustrating to scientists, as well as librarians, especially in comparison to free and easy access to MEDLINE and genomic data. In the case of ClinicalTrails.gov, the Congressional intent was to help more patients gain access to trials that might help them.

Once developed, however, PMC and ClinicalTrials.gov became key enablers of new public policies that emerged from separate series of events involving research advocacy groups, librarians and their professional associations, scientists, patients, journal editors, and the Congress. For PMC, the precipitating issue was lack of public access to the results of taxpayer-funded research. For ClinicalTrials.gov, it was outrage over deliberate omission of information about serious adverse drug effects in articles reporting the results of clinical trials. By late 2007, in separate actions, the U.S. Congress had mandated: (1) deposit in PMC of papers resulting from research funded by NIH, i.e., the

NIH Public Access Policy, and (2) early registration and summary results submission in ClinicalTrials.gov for the majority of trials of drugs and devices subject to regulation by the U.S. Food and Drug Administration (FDA). Many other research papers and trials became subject to similar requirements promulgated by other research funders. Early and complete registration of clinical trials has been required for subsequent publication of results in many influential journals since 2005.

The new requirements were highly beneficial to the public and to the missions of NIH, NLM, and health sciences and research libraries in general. As the policies were developing and evolving, NLM kept health sciences and research librarians informed and encouraged their efforts to educate and assist investigators within their institutions in meeting their new responsibilities. In many cases, new relationships were established between librarians and their institution's offices of sponsored research. Once laws were passed, serious penalties for non-compliance were defined, and prospects for enforcement increased, formal institution-wide approaches for assisting and monitoring compliance by individual investigators were needed to avoid serious consequences for the whole institution, e.g., denial of future research funding.

Librarians in grantee institutions were instrumental in working with the NLM's National Center for Biotechnology Information (NCBI) to define and test reporting capabilities that provide an institution-wide view of missing or stalled submissions of author manuscripts to PMC so that corrective action can be taken. Librarians and information specialists in institutions with NIH Clinical and Translational Science Awards (CTSAs) were among the first to set up regular interactions with NLM's ClinicalTrials.gov team to provide specific feedback on problems being encountered in expanded trial registration and results submission. They also promoted centralized support within their institutions for meeting the new requirements. Librarians' existing relationships with NLM and its staff served their institutions well in advancing compliance with the new requirements and helped to raise their profile within the research enterprise.

4. Conclusion

Don Lindberg involved librarians in every important research or development program at NLM described in this chapter and elsewhere. He was very focused on the education and training of the library workforce as evidenced by the multiple task forces, programs, and studies on these topics instituted during his tenure at NLM [9]. As Linda Watson, retired director of the Health Sciences Library, University of Minnesota and MLA past president, commented to Don in his oral history interview, "NLM programs and services have helped librarians to be able to continue to reinvent themselves. Whether it's outreach, whether it's informationist concepts, whether it's patient care, disaster, you've given us the tools to be able to reinvent ourselves successfully" [7,p.41].

I treasured the years I worked with and learned from Don. After a somewhat rocky start at MLA's 1992 Annual Meeting, the relationship developed into a mutually supportive experience where the library community encouraged NLM to make access to the databases free to the public which he did, and NLM supported a number of initiatives including health information literacy, expanded roles for hospital librarians, and the education and training for health sciences librarians. Don broadened my perspectives as well as that of health sciences librarians through his willingness to meet, meaningfully interact, listen, and learn. In my role as MLA Executive Director, I met with Don once

or twice a year for almost twenty years to exchange information about both of our organizations' programs and activities and the ways we could support each other and educate and evolve the profession to get quality health information to a variety of audiences. Don also attended MLA Board meetings when possible, gave an annual NLM update to the health sciences library community at MLA's annual meeting, and placed an MLA representative on the Friends of the National Library of Medicine, a group which he helped establish in 1986.

At his retirement event in 2015, Linda Walton M.L.S., MLA past president, eloquently summed up Don's impact on the health sciences library community saying, "Your fearless spirit of envisioning the next gateway of necessary tools and resources, and your willingness to prove nothing less than extraordinary has challenged us. From end-user searching, to bioinformatics, to disaster preparedness, you have led the way for librarians to develop and expand their expertise through the use of technology. This could only have happened because of your vision and the outstanding programs that NLM provides to the health sciences library community" [32].

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Partnering for Education and Career Development of Librarians and Information Specialists

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Abstract. Donald A.B. Lindberg M.D. was a strong proponent of self-improvement for all professions. He believed it was imperative for health sciences librarians to embrace lifelong learning as the Internet and networked information radically changed their work and opened new opportunities to increase their scope and impact. During Dr. Lindberg's 1984-2015 tenure as its Director, the U.S. National Library of Medicine (NLM) became an even more dominant influence on education and career development of health sciences librarians. This chapter focuses on the way NLM partnered with other institutions and organizations to ensure that education and training were consistently part of the roll-out of new NLM programs and services as they were implemented.

Keywords. Donald A.B. Lindberg M.D., U.S. National Library of Medicine, Education and Training, Medical Library Association, National Network of Libraries of Medicine

1. Introduction

When Donald A.B. Lindberg M.D. took over as Director of the U.S. National Library of Medicine (NLM) in 1984, NLM programs were directed primarily at health professionals and scientists, with librarians serving as the intermediaries to NLM systems and services. Beginning in 1966, NLM's Associate Fellows Program provided a yearlong experience for librarians that continues to the present day. A large component of NLM's involvement in direct training of health sciences librarians began following passage of the Medical Library Assistance Act (MLAA) in 1965. Although it authorized funds for masters-level education, the MLAA mandate to establish the Regional Medical Library (RML) Network had a longer-term impact on training of librarians. As NLM launched new services, such as the MEDLINE retrieval system in 1971, it worked with and through the Network to provide hands-on training for librarians as the logical strategy to make sure these services were used effectively.

Dr. Lindberg not only continued the emphasis on professional development for librarians, but greatly enhanced opportunities as part of the NLM's planning and development processes. Dr. Lindberg was a strong proponent of self-improvement through continuing education for all professions, and in his presentation to the 7th

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International Congress on Medical Librarianship in 1995, he spoke about the growing pains faced by libraries and librarians attributable to the influence of the Internet on their work. He urged librarians to "embark on a program of lifelong learning that will enable them to make optimum use of the advantages offered by modern technology" [1].

2. Librarians and the NLM – A Balancing Act

The relationship between the National Library of Medicine and the health science library community has evolved over the years and is well-described in Betsy Humphreys' 2001 Janet Doe Lecture for the Medical Library Association [2]. Humphreys illustrated how program decisions and new services at NLM had an enormous impact on health sciences libraries and librarians. For the most part, being able to tap into the extensive resources and expertise of the NLM gave medical librarians a leg up over their colleagues in other types of libraries. But this did not prevent librarians from expressing their concerns over NLM decisions which had an impact on their daily work lives.

It is impossible to describe the influence of Dr. Lindberg on the education and training of medical librarians and other information specialists without looking at the partnerships that NLM forged with academic institutions around the country and with professional associations. While many of these organizations had a relationship with NLM before Dr. Lindberg arrived on the scene, the nature and strength of those relationships changed. Academic health centers and their libraries are an essential link to NLM's impact on the education of librarians. Through their roles as regional medical libraries and resource libraries within the RML Network (renamed the National Network of Libraries of Medicine in 1991) and their coordinated efforts within the Association of Academic Health Sciences Libraries (AAHSL), these libraries provided education and training for not only their own staff, but for librarians and health information specialists throughout their communities.

The Medical Library Association (MLA), which represents professionals from health sciences information centers of all types and sizes, was and is the predominant provider of continuing education for librarians working in academic medical centers, community hospitals, nursing colleges, pharmaceutical companies, and a vast array of public health and non-profit health agencies. From 1964-1987, MLA had a formal structure in place in the form of the MLA-NLM Liaison Committee and used that link to expand and enhance its working relationship with NLM to the benefit of both organizations. In the agreement to disband the Committee in favor of special meetings when matters of substance arose, the MLA Board committed to reserving at least one hour of each annual meeting for an NLM Update. Throughout his tenure, Dr. Lindberg was a regular attendee at MLA annual meetings and lead speaker at the NLM Update sessions.

Partnerships between NLM and the library community proved to be highly beneficial over the years for the career development of health sciences librarians, but the relationship ran into some challenges along the way [2]. Several NLM initiatives during Dr. Lindberg's first years as Director set the stage for potential conflict between NLM and the library community. For example, in 1986, the Grateful Med search software was introduced as an interface that would enable individuals without search training to access the MEDLINE database [3]. Grateful Med was an evolutionary step because it opened NLM databases to remote individual users who might not have an affiliation with a hospital or medical center library.

In its enthusiasm to get the word out about the new user-friendly software, NLM inadvertently set off a controversy within the library community in 1989. A letter signed by Dr. Lindberg and sent to hospital administrators informing them about Grateful Med, failed to mention librarians or library services. In my own hospital, the letter was forwarded to me by my administrator and used as an opportunity to talk about this new access to MEDLINE. In many libraries, however, the development and promotion of services designed for direct use by health professionals was seen as an effort to bypass librarians and to downplay their expertise as intermediaries between end-users and database services. Librarians feared they would lose ground if administrators believed that health professionals could search without assistance by trained library professionals. In his 2014 oral history with Linda Watson, Dr. Lindberg gave his alternative view of this conflict. He believed that as amateur searchers, "doctors are not going to be anywhere close to as good searchers as medical librarians, but they'll admire them" [4].

In 1989, the NLM Board of Regents issued an outreach planning report with four recommendations to improve access to NLM information services "by every American health professional in all settings" [5]. This report was based on the work of a blue-ribbon panel (including librarians) chaired by Dr. Michael DeBakey and came to be known as the "DeBakey Report." The report called for NLM and RML network libraries to work together to ensure that information resources are available to all health professionals. It recommended that the RML Network be reconceived as a "field force" for developing, marketing, and distributing NLM products and services. Although the report emphasized the need for librarians to train health professionals to access NLM resources more directly, it also recommended increased funding for new training opportunities for health sciences librarians.

Thanks to the foresight of Dr. Lindberg, new NLM training initiatives brought librarians into partnership with physicians and other health professionals. Ultimately, this helped to promote the inclusion of librarians as equal members on multidisciplinary teams, including those producing comprehensive systematic reviews and meta-analyses on specific subjects.

3. The Woods Hole Experience

No other training effort had more impact on the development of librarians' knowledge and skills in the application of computers and information science in medicine than the Woods Hole Medical Informatics course (later the Biomedical Informatics Short Course at Woods Hole, and subsequently Georgia). Initiated by Dr. Lindberg in 1992 in cooperation with the Marine Biological Laboratory in Woods Hole, MA, this competitive training fellowship was funded by NLM and aimed at medical educators, medical librarians, medical administrators, and young faculty who had "the ability to become change agents in their institutions" [6-7]. For many librarians, participation in the week-long residential informatics short course was the most personal contact they had with Dr. Lindberg and his wife Mary. Course attendance became a badge of honor for many in the profession.

A 2005 survey of a random sample of past participants in the course from 1992-2001 found 64% of respondents subsequently were responsible for making strategic health care information-related decisions and 69% were responsible for training other people to use information technologies, systems, or tools [8]. Participants reported that the course changed their credibility levels and increased their confidence working in the

field of medical informatics. Taking the course alongside physicians, nurses and other health professionals gave librarians an opportunity to develop their networking skills at the same time they were learning about informatics. Hundreds of librarians benefited from participation in the informatics short course. Many have gone on to be informatics leaders within their institutions and the profession. Others have played the lead role in developing and teaching courses for librarians, medical students, nurses, and other health professionals.

4. NLM Planning Panel for Education and Training

As part of its long-range planning process, NLM assembled a planning panel on the education of librarians in 1994, with participation from a multidisciplinary team of health professionals, librarians, library school faculty, medical informaticians, and NLM staff. The resulting 1995 report offered a series of goals focused on four key areas: 1) evolving role of the health science librarian; 2) professional educational programs; 3) lifelong learning programs; and 4) recruitment, including minorities [9]. Woven into the final report was the establishment of "Challenge Awards" to support planning for implementation of specific report recommendations that required further study. During the 1995 U.S. fiscal year, seven awards were made, including to two university medical libraries and five professional library schools [10].

As an example of the impact of these awards, the M.L.S. program at the University of Pittsburgh added a specialization in health sciences librarianship, launched a recruitment plan to attract under-represented minorities, and designed a series of continuing education courses approved by MLA for their Academy of Health Information Professionals certification program [11]. Along with many tangible new programs and courses developed as a result of the challenge grants, the panel's report emphasized that the rapid changes occurring in medical and healthcare informatics required new ways of training in graduate programs and in continuing education for practicing librarians. Preparing librarians to step into new training and liaison roles was part of what was required.

In addition to the challenge grants, NLM took several steps in 1998 to implement the planning panel's recommendations. The NLM Library Associates Program was renamed to emphasize its Fellowship stature and was expanded from four to up to eight participants beginning in September 1998. An optional second year was added so the Associate Fellows could spend a year in an academic medical center, hospital, or other health-related institution. The purpose of the second year was to give librarians experience working with a multidisciplinary team to integrate library and information services into patient care, professional education, or research programs of the parent institution [12].

The panel's report also led to expanding educational opportunities for librarians in biomedical informatics. Beginning in 1998, all existing NLM Informatics Training Programs were offered additional funding and strongly encouraged to offer training through the curriculum suitable to those interested in health sciences libraries. By 1999, librarians were in place at four of the ten Informatics Training Programs. Furthermore, the Applied Informatics Fellowships were widely publicized to the library community as a means of supporting informatics training at a mid-career level. As medical libraries began to play a greater role in supporting researchers in fields such as molecular biology and genomics, there was a need to establish educational and support programs to address

the challenges their users were facing with all the new databases and retrieval and analysis tools.

Renata Geer M.L.S, a former NLM Associate working in NLM's National Center for Biotechnology Information (NCBI), saw the need for a basic course for librarians and led development of an "Introduction to Molecular Biology Information Resources," first offered in May 1997 as an eight-hour CE course at the MLA annual meeting [13]. Today a 14-week, self-paced course "Bioinformatics and Biology Essentials for Librarians: Databases, Tools, and Clinical Applications" is listed in the NNLM Class Catalog. This current version offers 30 hours of MLA CE credit. Librarians in the sciences have benefited tremendously from educational support provided by NLM to enhance their knowledge of and experience with a wide range of bioinformatics databases and research tools.

5. Training and Education Within the National Network of Libraries of Medicine

When Congress passed the MLAA in 1965, it gave NLM authorization and funding for training librarians and mandated establishment of the Regional Medical Library (RML) Network (renamed the National Network of Libraries of Medicine (NN/LM) in 1990). When Dr. Lindberg became the NLM Director in 1984, there were approximately 3,000 libraries in the Network, including academic medical libraries, libraries in hospitals and pharmaceutical companies, and other biomedical libraries. By the time Dr. Lindberg retired in 2015, the NNLM had grown to more than 7,000 members, including public libraries, information centers, and community-based organizations. Dr. Lindberg was a strong proponent of the NNLM and its critical role in bringing information services to health professionals, the general public, and underserved communities [14]. He also championed the role of the NNLM in the career development of health sciences librarians. Thousands of librarians received training either directly or indirectly through the NNLM during the 30 plus years of his tenure.

As MEDLINE and other NLM resources were developed and made available for searching, the training emphasis of the RMLs expanded to include more training for Network member librarians to be effective users of these new databases with a focus on librarians in hospitals, clinics, nursing and allied health professional schools, and public health societies and organizations. By 2001, training services were concentrated into the National Training Center and Clearinghouse (NTCC) at the New York Academy of Medicine. The NTCC later became the NNLM Training Office (NTO) and moved to the University of Utah [15].

With Dr. Lindberg's strong support, training in specialized areas grew as NLM provided additional databases on a wide range of topics. Dr. Lindberg thought network librarians should be knowledgeable about all NLM services, not just MEDLINE and other bibliographic databases. In the 1980s, HIV/AIDS resources began to be incorporated into the training curriculum as did toxicology and environmental topics - and in the early 1990s health services research and technology assessment resources.

In the 1990's, as public libraries began to provide Internet services to the community, it became clear that a large percentage of queries coming from the public were health-related. When MEDLINE became free on the Internet in 1997, many of the new users were members of the public. In 1998 NLM launched a pilot project "to learn about the role of public libraries in providing health information to the public and to generate information that would assist NLM and the NNLM in learning how best to work

with public libraries in the future" [16]. The pilot involved an early version of NLM's MedlinePlus consumer health website to obtain feedback from public library staff and their patrons.

Extra funding was added to the RML contracts to pay for consumer health coordinators in every region and during the 2001-2006 contract period, the NNLM developed a series of four consumer health courses targeted to public librarians. Although directed to public librarians and other community-based information specialists, these courses were often attended by health sciences librarians. The four basic courses became the core curriculum for the MLA Consumer Health Information Specialization (CHIS) described in the next section of this chapter.

Another area in which NLM had an impact on career development and training is emergency preparedness and disaster mitigation. Events such as a 2001 terrorist attack on the World Trade Center in New York City and a series of natural disasters along the southern coasts of the U.S. exposed the need to assure consistent availability of critical health information resources during national and regional emergencies. In the aftermath of Hurricanes Katrina and Rita in 2005, Dr. Lindberg was impressed by the work of NNLM libraries in providing back-up information access for health professionals, faculty, students, and patients and of public libraries in supporting displaced families. He envisioned the NNLM as playing a continuing vital role in this work, and beginning with the 2006-2011 RML contracts, there was a new emphasis on emergency preparedness.

NLM's long-range plan for 2006-2016 called for the NNLM to develop strategies for network libraries to provide back-up services for one another and to conduct training in emergency preparedness and response [17]. By 2008, NLM had launched its Disaster Information Management Research Center (DIMRC) "to make a strong commitment to disaster remediation and to provide a platform for demonstrating how libraries and librarians can be part of the solution to this national problem" [17]. Working with FEMA and other governmental units, DIMRC developed and/or identified a series of basic and advanced level courses aimed at training professionals in multiple fields to access, use, and manage information to support their institutions and communities in planning for, responding to, and recovering from emergencies and disasters [18].

As the incoming president of MLA and a former member of the 2006-2016 long range planning panel, I was keenly aware of the importance Dr. Lindberg placed on having the NLM play a central role in channeling health information resources to communities affected by disasters and also for preparing librarians to take on key responsibilities for managing access to those resources. Thus, I was not surprised to be approached by a member of the DIMRC staff at the 2010 MLA meeting about an NLM/MLA partnership to co-develop the new Disaster Information Specialization (DIS) that is described in the next section of this chapter.

6. Partnering with the Medical Library Association

The Medical Library Association (MLA) has been the primary source of continuing education (CE) for health sciences information professionals since the middle of the twentieth century. In the mid-1980s, MLA began to expand its CE program to a fully integrated professional development program. In 1989, MLA appointed a Knowledge and Skills Task Force that conducted a member needs assessment and crafted an educational policy statement, *Platform for Change,* that described the need for lifelong interdisciplinary learning for the field, provided concrete guidelines for graduate

programs, and acknowledged the need for a strong continuing partnership between MLA and NLM in attaining the goals of the document [19].

NLM responded to the recommendations in *Platform for Change* by convening the planning panel that resulted in the 1995 report "*The education and training of health sciences librarians*" described previously. One of the seven "challenge awards" made (to implement recommendations from the report) went to the University of South Carolina to partner with MLA to conduct a needs assessment of the MLA membership in 1996 to account for the extraordinary technological developments since the previous member survey in 1990. This synergy between NLM and MLA has enabled both organizations to advance educational opportunities for health information professionals that were aligned with common and mutually beneficial goals.

Over the years, MLA and NLM have worked on several collaborative projects and often acted as co-sponsors for the other's programs, including the establishment of the Consumer Health Information Specialization (CHIS) and the Disaster Information Specialization (DIS) mentioned earlier. MLA's CHIS credential, implemented in 2001, was targeted toward medical librarians, public librarians, librarians working in consumer health libraries, allied health professionals, information professionals, and anyone concerned with providing accurate and useful health information to the public at the right time and place. NNLM and MLA worked closely together to promote this education opportunity and provide in-person and online courses, based upon four courses developed by the NNLM. In 2021, MLA reported that more than 1,300 librarians, health and information professionals, and others had earned the CHIS and many more had taken consumer health information courses, another testament to Dr. Lindberg's vision of providing health information to the public [20]. It also has stimulated more librarians to reach out to their communities, participating in health fairs and other community events.

Dr. Lindberg's influence weighed heavily in the decision to develop the DIS credential as a collaborative project between MLA and NLM. Recognizing the untapped potential of libraries, librarians, and information services to aid in the nation's disaster management efforts, DIMRC worked with MLA staff to develop a curriculum that would address the core competencies needed to manage health information resources effectively as part of the national response to major disasters. The curriculum covers key concepts in disaster medicine and the public health field for librarians, as well as health information literacy for the disaster workforce. This specialization has been promoted at conferences and in articles and editorials in both library journals and journals reaching the emergency/disaster workforce, public health departments, and policymakers. As of 2021, nearly 200 people have qualified for DIS certification [20]. It represents an area of training that might not have been established without Dr. Lindberg's leadership and his belief in librarians as a group of professionals well positioned to provide these services.

NLM and MLA also have collaborated on several educational conferences. As a follow-up to the NLM and NNLM pilot project with public libraries in 1998, NLM held a colloquium in 2001 in conjunction with the American Library Association (ALA) midwinter meeting, co-sponsored by the NNLM, MLA and the Public Library Association (PLA), a division of ALA. Entitled "*The Public Library and Consumer Health: Meeting Community Needs Through Resource Identification and Collaboration,*" the program included presentations by Dr. Lindberg and several other NLM staff members [21]. The interaction between public librarians and health sciences librarians was very positive and led to mailings to public libraries in all 50 states, including a letter from Dr. Lindberg and the PLA President, along with bookmarks and

a poster about MedlinePlus.gov, promoting NLM's free resources available to all libraries.

Other education and career development collaborations between NLM and MLA have taken the form of projects to improve access to educational opportunities. MLA's Educational Clearinghouse, started in 1973, merged with the National Training Center and Clearinghouse (NTCC) Educational Clearinghouse database in 2011 to eliminate the duplication of effort between the two organizations, thereby making it easier for librarians to locate the best CE course for their needs [22]

In order to encourage minority students to choose health science librarianship as a career, the NLM provided funds for several years to "increase the size of MLA's existing minority scholarship, and to support, in partnership with MLA, the ALA's Spectrum Scholars program to attract students of color to graduate programs in library and information studies and for outreach to minority college and high school students" [23].

To demonstrate its commitment to the quality of health through health information-related research and to recognize Dr. Lindberg's encouragement of librarian involvement in research, the MLA announced in 2002 that it would establish the Donald A. B. Lindberg Research Fellowship with the goal of building an endowment to award up to $25,000 annually for work in pursuit of research related to health sciences libraries and librarianship [24].

In his MLA oral history interview with Linda Watson, Dr. Lindberg commented on his working relationship with Carla Funk, MLA's Executive Director from 1992-2015. He said "I compliment you on Carla Funk, who has been absolutely marvelous, a leader of MLA. We worked so smoothly and without a whole lot of folderol, and even written agreements just naturally supporting what we're trying to do, and we are having some pleasure in supporting what she's trying to accomplish and MLA is after. It has been a great pleasure and a wonderful partnership" [4].

7. The NLM/AAHSL Leadership Fellows Program

From a participants' perspective, the NLM/AAHSL Leadership Fellows Program is one of the most valuable collaborations with NLM. The Association of Academic Health Sciences Libraries (AAHSL) is affiliated with the Association of American Medical Colleges (AAMC). It "supports academic health sciences libraries and directors in advancing the patient care, research, education, and community service missions of the academic health centers through visionary executive leadership and expertise in health information, scholarly communication, and knowledge management" [25]. The Leadership Fellows Program was initiated in 2002 through the generous support of NLM and continues to this day with the planning and execution of the program done primarily by AAHSL. The year-long fellowships pair a group of mid-career librarians who have some management experience with mentors who are serving as library directors for AAMC member institutions. Fellows attend a capstone event that includes leaders from NLM, including Dr. Lindberg during his tenure as Director. Participants in the program have overwhelmingly found the experience to have had a positive impact on their career development and their levels of self-confidence. Over a period of 17 years, 92 fellows and 74 mentors have been part of this program, and as of 2019, 54% (47) of the Fellows had received a permanent director position [26].

8. Conclusion

Looking back over the more than 30 years when Dr. Lindberg was at the helm, examples abound of the ways NLM enhanced educational opportunities for librarians, some by providing hands-on training specific to a database or resource, and others by providing resources to partnering institutions and organizations to carry out the training. Dr. Lindberg was the prime mover behind some of these opportunities and supported all of them. NLM's outreach efforts led to additional funding for the RML Network which in turn, led to more training for health sciences librarians and increased emphasis on the role that librarians play in ensuring that health professionals in community-based settings can use NLM resources to practice evidence-based medicine. In partnership with the Marine Biological Laboratory in Woods Hole, MA, NLM provided an immersive week-long medical informatics fellowship for librarians to become more knowledgeable about applications of computers in medicine and to do so alongside health professionals and administrators in order to provide networking opportunities. Under the leadership of Dr. Lindberg, NLM built synergistic relationships with MLA and AAHSL to greatly enhance education and career development opportunities for librarians and information professionals serving health-related institutions and organizations.

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Section Three

Don Lindberg's Outreach Legacy at the National Library of Medicine

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Don Lindberg's Outreach Legacy at the National Library of Medicine

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Abstract. Friends and colleagues of Donald A.B. Lindberg M.D. came together to give tribute to his extraordinary contributions during his tenure (1984-2015) as Director of the U.S. National Library of Medicine (NLM). Dr. Lindberg died in 2019. The book, *Transforming biomedical informatics and health information access: Don Lindberg and the U.S. National Library of Medicine.* includes four sections. The ten edited chapters in section three (the Outreach section) are briefly summarized in this overview. As Associate Director for Health Information Programs Development, Elliot R. Siegel Ph.D. coordinated NLM's outreach programming under Dr. Lindberg's leadership from its inception in 1989 to his own retirement in 2010. Dr. Lindberg's legacy at NLM is one of new possibilities imagined, significant changes made in the mission and ethos of a venerable institution, and numerous successes achieved in a variety of settings and contexts. Like so much else Dr. Lindberg accomplished, these Outreach programs that profoundly changed the character of NLM would likely not have occurred without him. He made a difference.

Keywords. U.S. National Library of Medicine, Donald A.B. Lindberg M.D., Outreach

1. Introduction

Friends and colleagues of Donald A.B. Lindberg M.D. came together to give tribute to his extraordinary contributions during his tenure (1984-2015) as Director of the U.S. National Library of Medicine (NLM). Dr. Lindberg died in 2019. The book, *Transforming biomedical informatics and health information access: Don Lindberg and the U.S. National Library of Medicine,* includes four sections. The ten edited chapters in section three (the Outreach section) are briefly summarized in this overview.

1.1. Planning for Outreach

When Dr. Lindberg arrived at NLM in 1984, he brought with him new ideas that motivated staff to pursue with him exciting opportunities for change. Among these was the need for a comprehensive Long Range Plan, the first of its kind for NLM, that was completed in 1987 [1]. A variety of exciting new program possibilities were identified, several of which are discussed in other sections of this book. One emerging possibility, subsequently recognized by Congress encouraged NLM *"...to develop an outreach program aimed at... [the] transfer of the latest scientific findings to all health*

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professionals …" [2] The mission of NLM was also explicitly amended to add the function to *"Publicize the availability of [its] products and services…"* [3] This was pursued in greater depth as an update to the Plan, the 1989 *DeBakey Report* that, in effect, details the origin story of NLM's outreach programs [4].

The Plan's focus was on connecting unaffiliated health professionals in rural and underserved communities to medical libraries. This ultimately grew to an ambitious program of Outreach that was national in scope and intended to serve the diverse information needs of biomedical scientists and research scholars, practicing health professionals, patients, their families, and the public at large.

The chapters in this section report on the influence and impact Dr. Lindberg had on Outreach, along with the programmatic and intellectual contributions he made in the conceptualization of a project and/or its implementation, sometimes with his own considerable personal involvement. The chapters do so through the words and personally recounted stories as told by colleagues and friends who worked with him, and whose own significant contributions are also detailed therein.

2. Consumer Health Outreach

When the Internet made possible access to NLM's online information resources without a telecommunications cost to the Library, NLM's institutional outreach commitment was significantly expanded to include 'consumers' -patients, families, and the public. The chapter by **Kathleen Cravedi M.S.** on Consumer Health Information details several 'revolutions,' including a whirlwind of activity in the 1990s she helped orchestrate as head of NLM's Office of Communications and Public Liaison [5]. Free MEDLINE (the literature citation and abstracts database) had its beginning with the ceremonial launch of Internet Grateful Med by Michael DeBakey M.D. and Sen. Bill Frist in June 1996 at a Friends of the NLM conference. It was followed in April 1997 with a bipartisan congressional press briefing sponsored by Sen. Tom Harkin and Sen. Arlen Specter.

Two months later, it culminated with Vice President Al Gore conducting the first free Internet search of MEDLINE using the new PubMed search system, under the watchful eyes of Dr. Lindberg and NIH Director, Harold Varmus M.D. This was an era in which influential lawmakers on both sides of the aisle unabashedly championed the role of government in protecting the health of the nation's citizens. It also provided political cover enabling NLM to greatly expand the reach of its premier information services without the cost of searching being a barrier to good health. One year later, in 1998, NLM launched the MedlinePlus database and portal whose contents were especially written in plain language, in both English and Spanish. NLM was now firmly in the service of advancing consumer health for everyone.

3. Outreach for Underserved and Minority Populations

With these new capabilities came a special commitment by Dr. Lindberg and his outreach team to enhance the capacity of underserved and minority populations to make use of NLM's health information resources on an individual level, and in support of the societal goal of reducing health disparities amongst Black, Hispanic, and Native American populations.

3.1. Environmental Health Outreach

The environmental justice movement had its roots in the 1980's protests against the placement of toxic waste dumps within communities of color that had limited political influence or economic clout. Dr. Lindberg and his outreach team supported that fight with the establishment in 1991 of the Environmental Health Information Partnership (EnHIP) that played to NLM's strength of harnessing the power of health information to help mitigate the risks posed by unsafe exposures to toxic substances. The chapter by **Gale A. Dutcher M.S. M.L.S. and John C Scott M.A.**, presents the story of unique partnerships that began with leading faculty at Historically Black Colleges and Universities (HBCUs) and, over the years, expanded by Dr. Lindborg to include institutions serving Hispanic and Native American communities [6]. The capacity-building model they developed deployed computer equipment and telecommunications purchases, along with user training. It would become NLM's longest running outreach program.

3.2. HIV/AIDS Outreach

At no time in the early 1990's was the need greater for trustworthy and authoritative information than amongst gay men and communities of color struggling with the deadly HIV/AIDS epidemic. Science was turning the corner on reversing an AIDS diagnosis as a likely death sentence, but much more remained to be done in the laboratory and in the community. **Gale Dutcher's** chapter on HIV/AIDS traces the beginnings of NLM's second longest-running outreach program, spawned from a landmark NIH conference in 1993 during which the activist public was given a very large microphone and whose appeal for freely accessible life-saving information was dramatically made [7]**.** Dr. Lindberg heard the message and immediately mandated cost-free searching of NLM's HIV/AIDS databases, an action that anticipated by several years free MEDLINE. But those who would benefit most at the grassroots level often had limited awareness and technical capability to take advantage of the offering. An AIDS community-based information outreach program (ACIOP) was quickly created and launched. It has since funded more than 300 projects reaching thousands of people over the span of decades, evolving with changing needs and opportunities. NLM supported the acquisition of computer equipment, Internet services, user training, and the creation of locally themed and targeted outreach initiatives built atop NLM's national information resources and services

3.3. Mentoring Urban Youth

Institutional capacity building is important of course, but it probably places second best to the development of people beginning at a young age. It took the audacious vision of three emergency department physicians in New York City in 2006 to imagine a Mentoring in Medicine (MIM) program geared to urban youth who have a dream to become healthcare professionals. The chapter by **Lynne Holden M.D.** shows how it was done through live and virtual programs, in school and after-school, utilizing age-specific learning materials, along with culturally themed and engaging exercises [8]. Dr. Lindberg was thoroughly hooked, and he backed MIM with financial support, and he gave of his energy and that of Mary Lindberg who both enthusiastically committed

themselves to an activity they thoroughly enjoyed, and which gave them great personal pleasure.

4. Outreach Evaluation

It is generally accepted in the evaluation community that people do not like themselves or their work to be evaluated by others. At NLM there was also the perception that its online users must be protected from intrusive questions and questioners. Earning trust is therefore critical, and setting conditions where privacy is respected, participation is voluntary, and the benefits of evaluation are achieved with no user complaint, all go a long way towards overcoming these concerns. Important lessons learned and supported by a new Library-wide ethos championed by Dr. Lindberg who was a strong proponent of evaluation from his earliest days at NLM.

4.1. Are We Making a Difference?

A pointed question asked by Dr. Lindberg one morning at a senior staff meeting. He wanted to know if we are asking ourselves how effective are NLM's products and services? Are we reaching the people who should be our users? Are we meeting their needs? What are the benefits and outcomes? How might our products and services be changed and improved in response?

He was thinking specifically of NLM's premier offering, MEDLINE, which would soon be subjected to a major first-time evaluation under his guidance using the Critical Incident Technique. The question would also be asked of our outreach programs as well: are we making a difference? The chapter by **Frederick B. Wood M.B.A., D.B.A. and Elliot R. Siegel Ph.D**. addresses two Lindberg mandates - the need for a robust evaluation capability NLM-wide, and a well-funded outreach program that not only reaches for the low-hanging fruit but is also willing to experiment with novel approaches having moderately high risk and the prospect of significant reward [9]. Two defining evaluation contributions were developed during Dr. Lindborg's tenure.

4.1.1. Guide to Planning and Evaluating Health Information Outreach

NLM commissioned the publication of an outreach evaluation Guide intended to fill the knowledge gap of outreach programmers within NLM and collaborators in the field who typically had little or no formal program evaluation experience. A complementary evaluation consultancy also was established to support outreach projects undertaken in the field. Examples discussed in depth in the chapter are outreach projects with Native American tribes in the Northwest (Tribal Connections) and Hispanic communities in the Lower Rio Grande Valley of Texas. All these initiatives were jointly conceived and evaluated in partnership with the National Network of Libraries of Medicine (NN/LM) which is described in a companion chapter in the Outreach section of this book (see section 5).

4.1.2. Internet/Web Evaluation

Not to be content solely with user satisfaction surveys and usability testing, NLM undertook a multidimensional approach to evaluation under Dr. Wood's leadership. The

full range of methodologies is described in the chapter. Among them, NLM experimented with and developed new tools to evaluate the performance of the Internet: end-to-end performance testing. If we are migrating users (domestic and foreign) to the Internet, Dr. Lindberg was rightly concerned this increasingly important means of accessing NLM's products and services, especially by communities already known to have uneven access to the Internet, should function at a level sufficient for their needs. Identifying communications bottlenecks became an obligation and a part of NLM's outreach mission. An interesting test case was pursued following criticism by some foreign users in the Internet's early days, that Americans unfairly consumed all the bandwidth thus making access to NLM's services difficult. But testing clearly showed Americans were asleep when businesses at the other end were responsible for the slow service. Fix your local connections was the advice Dr. Lindberg offered.

5. A Field Force for Outreach

NLM is fortunate to have a strong and committed outreach partner in the embodied of the 8000-member National Network of Libraries of Medicine (NN/LM), now the Network of the NLM, as it includes a large contingent of public libraries. As a force for outreach initially identified in the 1989 *DeBakey Report*, NLM's Library Network has a stellar past going back decades, helping NLM support a myriad of tasks and functions (collection sharing consortia, interlibrary loans, etc.) that could not be fulfilled efficiently alone by the NLM mothership in distant Bethesda, MD. The same concept held true in the more recent past for outreach and evaluation.

The chapter by **Jean P. Shipman M.S.L.S., Catherine M. Burroughs M.L.S., and Neil Rambo M.L.** describes a variety of outreach functions carried out by the NN/LM in collaboration with NLM [10]. These include many locally initiated outreach projects, as well as those conceived by NLM staff but needing local partners to implement and evaluate them successfully. The Outreach Evaluation Resource Center (the evaluation consultancy noted previously), is a service provided by the NN/LM, and *Measuring the Difference: Guide to Planning and Evaluating Health Information Outreach* was jointly conceived and executed with the health sciences library at the University of Washington. Dr. Lindberg recognized the unique and critical roles played by the NN/LM, as did those of us in NLM's Office of Health Information Programs Development who relied heavily on its member libraries as advisors, partners, and local ambassadors who facilitated access to the local communities they served.

6. International Partners and Outreach

Beginning in 1966, NLM established *quid pro quo* collaborations with international medical libraries and information centers around the world to provide local access to the MEDLINE database in the form of leased magnetic tape technology. In return, NLM received revenue from searches performed by the International MEDLARS Centers, and assistance with indexing foreign language publications for MEDLINE. These mutually beneficial arrangements numbered 17 in 1987 and reached 20 in 1997, including the Israel MEDLARS Center, which opened in 1994 and operated solely as a local Internet

resource center providing direct access to NLM's online information resources. Intended by Dr. Lindborg as an innovation in direct and low-cost user access to NLM, it proved instead to be the harbinger of disruptive technology. With the advent of free Medline in 1997 and the ubiquity of Web-based searching, the need for locally provided access to MEDLINE services greatly diminished, and we witnessed the effects that rendered the IMCs largely obsolete.

6.1. BITNIS

Even in the heyday of the International MEDLARS Centers, accessing NLM's information resources by users in developing countries was generally prohibitively expensive and impractical, often as difficult as accessing it directly from NLM. An imaginative telecommunications innovation pieced together by a Chilian research scientist, and a computer scientist offered a practical workaround (store-and-forward email searches) that utilized a locally available NASA satellite link to establish a gateway system that interconnected BITNET and NLM's main database server. In his chapter, **Victor Cid M.S.** (the computer scientist) traces the development of BITNIS (BITNET to NLM Intercommunication System) from its initial launch in 1988, to its maturity from an experimental to a production system serving users in 56 countries throughout Latin America and the newly independent states of the former Soviet Union [11]**.** As with the MEDLARS Centers, the availability of MEDLINE services free of charge from NLM on a more widespread globally accessible Internet led to the sunsetting of BITNIS. The concept had appealed greatly to Dr. Lindberg who was intrigued by the imaginative use by Mr. Cid of computer and information technology, along with his knitting together a highly unusual network of domestic and international institutional collaborators that literally 'bridged the information gap before the Web'.

6.2. Multilateral Initiative on Malaria (MIM)

Malaria research scientists working in Sub-Saharan Africa experienced similar communications difficulties, but these persisted in 1997 and beyond as access to the Internet itself was frequently impossible due to hostile terrain and the physical absence of broadband communications infrastructure in remote areas where the research laboratories generally were located. NIH Director Harold Varmus M.D. and Anthony Fauci M.D., the renowned infectious disease scientist whose Institute was supporting malaria research in Mali, approached Dr. Lindberg for help, knowing of NLM's recent successes with Tribal Connections on Indian reservation. It was seen as an opportunity to make a difference, and Dr. Lindberg accepted the challenge and tasked Dr. Siegel with managing the effort on behalf of NLM. Subsequently, NIH and NLM assumed responsibility for a new communications initiative within the overall Multilateral Initiative on Malaria (MIM) framework. whose goals were to coordinate and enhance malaria research funding and aid capacity-building building efforts in malaria-ravaged Africa. Enhanced and reliable communications capacity was clearly needed to support isolated African scientists' interpersonal communications via email, proposal writing, and literature searching. Dr. Varmus subsequently learned during a briefing by Dr. Siegel that communications connectivity to the journal literature might be insufficient to enable access by the African scientists if the articles were hidden behind an unaffordable publisher-imposed paywall. This motivated Dr. Varmus to become actively engaged in

the Open Access movement that led to the establishment by NIH/NLM of the PubMed Central repository of full-text journal articles.

6.2.1. Multilateral Initiative on Malaria Communications Network (MIMCom)

The chapter by **Julia Royall M.A.**, describes her body of work in Africa, which was enthusiastically supported by Dr. Lindberg [12]. Ms. Royall brought to NLM prior experience in satellite communications, and a strong interest in Africa. MIMCom, and the satellite communications technology (VSAT) she used proved very effective in enhancing or introducing Internet connectivity to medical literature and other online information resources at 27 malaria research sites in 14 African countries. The strategy was shared bandwidth across sites, thus optimizing cost efficiency and effectiveness at each. Pay for what you use, while the underlying networking technology would be in place and scalable. It was a step-by-step building process, demonstrating success at initial sites that engendered confidence, trust, and adoption at new sites down the line. Success was achieved and, at least on the communications side, this enabled a sustainable capacity for research funders and partners alike at each site. Ms. Royall also discusses her efforts to document the impact the new technology had on African scientists, reported in their own words, and very much in the spirit of answering the question, *are we making a difference?*

7. Native Voices Exhibition

Two very important chapters make up the end of the Outreach section. They are special as a tribute to the vision and compassion of Don Lindberg whose interest in Native Americans began as a young third-year medical student doing an in Phoenix, AZ that also took him to the local Indian Health Service Hospital. He never forgot that experience, which generated a latent desire to eventually do something to help the Native American community. This desire was reinforced by his continually growing awareness of health disparities in Indian Country.

The first chapter by **Frederick B. Wood M.B.A., D.B.A., Anne R. Altemus M.A., and Elliot R. Siegel Ph.D**., tells the story of how that commitment was realized through a years-long scholarly and humanistic program of outreach to Native Americans, and culminating in a unique exhibition that benefitted from the unrivaled story telling capability that is a strength of NLM's History of Medicine's exhibition program [13]. Born of the initial Listening Circles and numerous trust-building visitations that spanned nearly a decade in the making, the *Native Voices Exhibition: Stories of Health, Wellness, and Illness from American Indians, Alaska Natives and Native Hawaiians* opened in 2011, along with traveling iterations throughout the decade. The exhibition features engaging videographed stories as told to Dr. Lindberg in revealing personal interviews with hundreds of Native elders and healers he interviewed in Alaska, Hawaii and the Lower 48. They recounted the epidemics, cruel government policies, and the inhibition of Native culture of the past, as contrasted with contemporary stories of renaissance, recovery, and self-determination.

At its core, it is a unique cultural asset of recorded history and a living testament to the inspired work of Native elders and healers who gave of their time and selves. Special kudos to Dr. Wood who, from the start, was a serious student of Native healing practices and served as a valuable internal resource to the outreach team as it navigated these new

learning experiences. The authentic beauty of the exhibition interviews would not have been possible without the inspired, professional videography and technically creative contributions of NLM's audiovisual team, led by Anne Altemus and John Harrington. They connected Dr. Lindberg's passion for photography with his encouragement to shoot b-roll when not recording interviews. "*Chase the clouds, and get some good stuff!"* he said, as they prepared for a drive toward Denali in Alaska. I will never forget John chasing the setting sun as it illuminated the shadowed tombstones of the historic Kalaupapa cemetery in Hawaii.

7.1. Reflections

The second chapter by **Katherine Gottlieb D.P.S., M.B.A, Cynthia Lindquist Ph.D., Theodore A. Mala M.D., M.P.H. and Marjorie Mau M.D., M.S.** contains personal reflections on Dr. Lindberg and the Native Voices exhibition as told by four amazing Native American leaders and friends [14]. They were instrumental in the successful development of the exhibition, providing invaluable guidance, insight and history to Dr. Lindberg and the outreach team.

Significantly, they enabled trusted access to the Native elders and healers who told their stories to Dr. Lindberg for this unique exhibition and for posterity. As health experts and educators, they share a collective experience bringing together Western Medicine at the intersection with the traditional healing and wellness cultures of Alaska, Hawaii, and Indian Country. NLM's outreach to Native Americans benefitted immensely from their friendship and contributions, and from colleagues in their communities.

8. Conclusion

It is very clear NLM would be a far different place had Don Lindberg not been its director. To be sure the needs and interests of research scientists and scholars, and health care providers of various stripes would have continued to be well served, as well as health sciences librarians in their traditional roles. As the chapters in the first two sections of this book attest, Dr. Lindberg's interests and initiatives were pursued with intelligence and gusto, and he achieved tremendous success in their outcomes. In the process, he earned the gratitude, respect, and trust of his colleagues with whom he collaborated.

But our "George Bailey' also saw other unmet needs: isolated healthcare professionals in remote settings; underserved and underrepresented minority healthcare providers and the disadvantaged patients they served; and the public, whose needs are also addressed in the second section of this book. All became beneficiaries of a robust program of outreach that not only sought to bring authoritative and trusted health information to a greatly expanded universe of users, but also to address from NLM's position of strength as a health information provider the inequities and consequences of health disparities. These are the Lindberg stories recounted in the Outreach section.

There were many memorable experiences along the way. One incident in particular stands out. Early in our outreach travels to connect with Native peoples in Hawaii that would ultimately culminate in the Native Voices Exhibition, our local collaborators in Honolulu organized a Listening Circle with Native Hawaiian community leaders and elders**.** In an oral history interview conducted by Linda Watson for the Medical Library

Association in 2014, Don Lindberg recounted an experience that those of us present thought might derail our outreach efforts in Hawaii before they began [15].

"I'd been to lots of Indian places, but I've never been to Hawaii or Alaska. And both turned out to be wonderful people, wonderful places. But the first take in Hawaii was very, very negative. They essentially treated us as one more band of whites from the outside here to take advantage of them some way or another."

(Watson: "Because they didn't know you yet and they didn't trust you.") "Yes. Right, they sure didn't. And so, they told me in a big public meeting that they had their secrets. They knew how to cure AIDS, for example, but don't expect them to tell me. So that was a very painful meeting because it was very public, and we had intended to be nice. And so, I ended up standing up and saying, Wait a minute. Let me tell you something. Here's the NLM. Here's the way it works. Please don't tell me any secrets because I don't have any secrets. Anything you tell me is available free forever to anybody. Any secrets you keep. And it did shut down conversation. There was a sort of radio silence. And I could see them thinking, well, this guy is a son of a bitch but at least he's honest. I just left."

Of course, Don went back. Many times. Stories previously untold outside the Native Hawaiian community were told to him, perhaps some of them were formerly secrets. They were told with trust that they would be respected and shared publicly for the benefit of improving non-Native peoples' understanding of their lives and cultures, and their sacred traditions of Native health and wellness. Don had earned their trust.

I had the privilege of coordinating NLM's outreach programming under Don Lindberg's leadership from its inception in 1989 until the time of my own retirement in 2010. The Native American outreach work that led up to the Exhibition affected me greatly, as it did Don. We both came to learn, understand, and appreciate Native Healing during our many visits, especially his countless videographed interviews with Native healers - Kupuna, like the late Aunty Aggie Cope whom we loved. They helped shape his personal vision for what the Exhibition would seek to accomplish, and in the end his Native American friends said he got it right.

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NLM's Revolution in Consumer Health Information to Improve Patient Outcomes

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Abstract. Under the leadership of NLM Director Donald A.B. Lindberg M.D., the National Library of Medicine (NLM) continued to promote its services to the nation's health care professionals and scientists. With support of the U.S. Congress, it initiated new communications and outreach programs and services directed at the general public that revolutionized their access to information as well. Because effective health communication must be tailored for the audience and the situation, Lindberg supported the development of online health information tools designed to help consumers find free, comprehensive, timely, and trustworthy sources of health information that, ultimately, can improve patient outcomes. New and popular consumer-friendly websites were championed by Lindberg, including MedlinePlus, and ClincialTrials.gov, and he formed unique partnerships with national physician organizations to educate their patients about reliable sources of health information from the NLM. A new era of timely and trusted online health information for the general public began in 2006 under Lindberg's tenure culminating in the development, publication and distribution of NIH's first consumer magazine, NIH MedlinePlus, featuring the research and findings of the NIH. In his effort to improve patient outcomes, Dr. Lindberg revolutionized the Library's outreach capabilities and successfully expanded its mission to serve not only health professionals and scientists, but also consumers nationwide.

Keywords. U.S. National Library of Medicine, Donald A.B. Lindberg M.D., outreach, consumer health.

1. Introduction

When Donald A. B. Lindberg M.D. arrived at NIH in 1984, NLM had a straightforward mission: to serve health professionals and scientists primarily through libraries. This function was expanded in 1989 with a new emphasis on serving health professionals unaffiliated with a health sciences library and/or located in remote or underserved areas of the country [1]. There was, however, no attempt yet to serve the general public. While he continued to promote NLM's services to health professionals, beginning in the early 1990s, Lindberg began to develop and support outreach and communication activities directed at the consumer. Their technical development is described in detail elsewhere in this book. See for example [2].

Today, we take this second prong of the NLM mission for granted. Here's the story of how it came to be from the personal perspective of Kathleen Cravedi M.S., who served under Dr. Lindberg as Director of the Office of Communications and Public Liaison.

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2. Lindberg Promotes NLM Information Services to Consumers

One of Lindberg's earliest efforts to establish a focus on public outreach was initiated in 1996 by his creation of a NLM Board of Regent's Subcommittee on Outreach and Public Information. The Subcommittee was chaired by the famous cardiovascular surgeon Dr. Michael DeBakey who, a few years earlier, had chaired the panel of the Board whose report jump started a new generation of outreach initiatives created and implemented by Dr. Lindberg and his outreach team [1]. His sister, Dr. Lois DeBakey, a scientific communications professor at Baylor College of Medicine also served on the Subcommittee and as a consultant to the NLM Board of Regents. Both DeBakeys shared Lindberg's view that the American public should have the same access to the medical literature that physicians and other health professionals used in their daily practice of medicine. Under Lindberg's dynamic leadership, they also encouraged the "Outreach" Subcommittee to recommend that the NLM drastically increase efforts to ensure that its unparalleled information resources be fully utilized by scientists and health professionals around the globe and shared with the consumers as well [3].

In June 1996, Lindberg held a press conference to launch Internet Grateful Med at the annual conference of the Friends of the National Library of Medicine at Georgetown University [4]. The event, hosted by Lindberg, featured Dr. DeBakey and Senator Bill Frist, (R-TN), a physician and surgeon, who conducted the first Internet search via Internet Grateful Med – a program for searching MEDLINE via the World Wide Web. Also speaking at the event were members of the Odone family whose true story was immortalized in the Hollywood's academy nominated film *Lorenzo's Oil.* The Odones, who lived six blocks from the NLM said they found a treatment for their son's terminal illness by researching the medical literature at NLM. They said, with Internet Grateful Med, all people could now have the same access to the Library's resources no matter where they lived in the world.

The DeBakeys personally marketed NLM products to the media, convincing Ann Landers to devote a column to NLM information services and getting popular medical TV shows such as *ER* and *Chicago Hope* to mention NLM's MEDLINE in more than eight episodes resulting in an explosion in the usage of NLM's online information resources. Dr. DeBakey produced a print campaign with the National Network of Libraries of Medicine (NNLM) called "*Medical Questions? Medline Has Answers,"* and a TV public service announcement featuring DeBakey called "*Good Information is the Best Medicine."*

In testimony before a House Appropriations Subcommittee on Labor, HHS on April 15, 1997, Dr. DeBakey urged Congress to improve public access to health information. As a direct result of his testimony, MEDLINE became free to the public in that same year, and a fact highlighted in a 1997 bipartisan congressional press briefing sponsored by former Senator Tom Harkin, D-IA, and the late Senator Arlen Specter (R-PA). Then Vice President Al Gore, assisted by David Lipman, M.D., Director of NLM's National Center for Biotechnology Information, conducted the first free Internet search of MEDLINE via PubMed (See Photo 1). Gore noted that "free Internet access to MEDLINE might do more to reform and improve the quality of health care in the U.S. than anything in a long time." "The National Library of Medicine's debut of free Web-based searching could not be timelier," said NLM Director Lindberg, "The health care delivery landscape is changing. Citizens are increasingly turning to the Web as a source of information to improve their daily lives, including their health. So, it is vital that they,

and the health professionals who serve them, have access to the most current and credible medical information" [5].

Photo 1. Ceremony on Capitol Hill, June, 26, 1997. On this occasion, Vice President Albert Gore (sitting) introduced free MEDLINE searching via the Internet and demonstrated a new system developed by the library called PubMed, which simplified searching for online medical information by researchers and the public alike. Standing, from left: Suzanne McInerney, David J. Lipman, MD, Director, National Center for Biotechnology Information (NCBI); Harold Varmus, MD, 1989 Nobel Laureate in Physiology or Medicine, and Director, National Institutes of Health, and NLM director Lindberg.

Subsequently, the volume of MEDLINE searches has increased remarkably, from 8.5 million a year in 1997 to over 120 million a year later, and nearly 400 million soon thereafter. And, about one-third of the searches were being done by consumers, indicative of the increasing public appetite for health information.

3. Lindberg Champions the Rise of NLM Consumer-Friendly Health Websites

Considering this major new group of users of NLM's medical and scientific database MEDLINE, Lindberg commissioned the creation of a new consumer-friendly database called *MedlinePlus* which debuted on October 22, 1998 [6]. Its mission was to present high-quality, relevant health and wellness information that would be trusted and easy to understand in both English and Spanish. Lindberg wanted to feature health information on surgical procedures, clinical trials, medical professionals and facilities, drugs, and medical terms, among other topics, available to the consumer anytime, anywhere, for

free. And Lindberg did not permit advertising on the website, nor did he want the website to promote or endorse any product or company.

By 2018, 277 million users viewed MedlinePlus more than 700 million times. The website now provides information about the symptoms, causes, treatment, and prevention of more than 1,000 diseases.

A new era of timely and trusted online health information for the general public began, stimulated by an NLM initiative to help the public use online health information. In January 2000, Dr. Lindberg announced NLM support for 49 electronic health information projects in 34 states, affecting rural, inner-city, and suburban areas. In announcing the projects, Lindberg noted, "We are supporting the increase in Internet access in a variety of settings, from middle schools serving low income and educationally underserved students to shopping malls and senior centers," he said. "These are imaginative and well-targeted projects that will help us determine how we can best provide millions of Americans who are still not connected to the Internet with access to health information. They will stimulate medical libraries, local public libraries, and other organizations to work together to provide new electronic health information services for all citizens in a community" [7].

In addition to Lindberg's efforts to increase consumer access to health information on the Internet, he was encouraging the development of numerous NLM consumer-friendly health websites as well. *ClinicalTrials.gov*, now the world's largest trial registry and a unique source of summary results data for many trials, was launched soon after in February 2000, providing patients, families, and members of the public with easy access to information about the location of clinical trials, their design and purpose, and criteria for participation [8]. Today, consumers can explore more than 375,000 research studies that are available in all 50 states and in 220 countries worldwide.

In 2003, Lindberg directed the NLM to join the National Institute on Aging to launch *NIHSeniorHealth.gov*, the first government website designed for older adults that featured authoritative, up-to-date information from the NIH, in a format that addressed the cognitive and visual changes that come with aging. The website was launched in an October 23, 2003, press briefing requested by Senator Tom Harkin (D-IA) and co-hosted by NLM Director Lindberg and National Institute on Aging Director Dr. Richard Hodes [9] (See Photo 2). In his opening remarks at the press briefing, Lindberg noted that "the use of the Internet for health information is increasing dramatically," and he added, "but the small type, low contrast, and difficulty in navigating around many sites have been obstacles for seniors. *NIHSeniorHealth.gov* corrects many of those problems, as well as providing health information that is the best that NIH can offer." Dr. Hodes said, "The way in which people think, learn, and remember, changes with age." He added, "This new web site is based on the latest research on cognition and aging and should prove to be an accessible and understandable way for seniors to find information about their health."

Photo 2. (From left to right). National Institute on Aging Director Richard J. Hodes, M.D., Senator Tom Harkin (D-IA), NLM Director Donald L.B. Lindberg, M.D., and Joyce Backus, Lead Systems Librarian, demonstrate and launch *NIH Senior Health* in an October 23, 2003, press briefing on Capitol Hill.

To develop the website, the NIA and NLM brought together researchers who study cognition, web site designers, and communications experts at the two Institutes to fashion a site that was easy for older adults to read, understand, remember, and navigate.

For example, the site featured large print and short, easy-to-read segments of information repeated in a variety of formats -- such as open-captioned videos and short quizzes -- to increase the likelihood it would be discovered and remembered. Consistent page layout and prompts help older adults move from one place to another on the site without feeling lost or overwhelmed. Each topic provided general background information, quizzes, frequently asked questions (FAQs), open-captioned video clips, transcripts for the videos, and photos and illustrations with captions. *NIHSeniorHealth.gov* also had a "talking" function, which allowed users the option of reading the text or listening to it as it is read to them. Finally, in addition to being senior-friendly, the new site was one of the first Internet websites to comply with Section 508 of the Rehabilitation Act of 1973, making it accessible for persons with disabilities.

NIHSeniorHealth.gov was retired on August 1, 2017. Many of the design approaches first developed on *NIHSeniorHealth.gov* have become best practices for Internet accessibility. These innovations included text resizing, changing color contrast, text-to-voice, "chunked" content, and the use of plain language. Today, innovations in technology have brought us to a point where the pioneering design features of *NIHSeniorHealth.gov* are now widely available on Web site at the National Institutes of Health and throughout the Internet.

4. NLM Partners with Physicians Who Prescribe MedlinePlus to Their Patients

In 2003, Lindberg formed partnerships with physician and health professional organizations (the American College of Physicians, the National Medical Association, the National Alliance for Hispanic Health, etc.) to educate patients about reliable sources of medical information available from the NLM [10]. In partnership with these organizations, NLM launched a campaign called *Information Rx*, which supplied prescription pads, and other promotional materials to health providers to point their patients to trusted NIH health care information. Press conferences were held in Iowa, Georgia, Florida, and Pennsylvania to alert consumers to the campaign and to increase awareness about other new NLM online health information services. In launching the *Information Rx* project in Georgia, Lindberg said that "as a physician myself, I believe that an informed patient is a 'better' patient." Lindberg added, "Patients armed with good health information tend to take better care of themselves, to take their medications as directed, and to feel that they're in partnership with their doctor, taking an active role in their own health and wellness."

The *Information Rx* project was a successful concept [11]. NLM found that physicians were eager to point their patients to good sources of health information on the Internet and the information prescription pads provided a good vehicle to do so. Research also indicated that more than 70% of patients were more likely to go to a website prescribed by their doctor. Ultimately NLM stopped distributing paper prescription pads in favor of experimenting with a more efficient and scalable protocol to connect physician's Electronic Health Record (EHR) systems directly to MedlinePlus, where individual patients could be referred electronically to information relevant to their needs [12].

To comply with a Senate Appropriations Committee request to NLM to increase consumer awareness of NIH funded research findings, Lindberg also found physician offices to be the logical place to fulfill this Senate requirement. Building on the success of NLM's *Information Rx* project, Lindberg championed the production of NIH's first consumer health magazine, *NIH MedlinePlus*, to be distributed to the public free of charge in physician offices nationwide.

5. NIH MedlinePlus the Magazine Debuts

In response to a Senate Appropriations report urging NLM to increase public awareness of NLM services, Lindberg created *NIH MedlinePlus* – a free bilingual, consumer health magazine in print and online, and NIH's first consumer health magazine. The magazine was developed by Lindberg in consultation with key NLM staff, including Donald King, M.D., Deputy Director for Research and Development; Kathy Cravedi, Director of NLM's Office of Communications and Public Liaison; Elliot Siegel, Ph.D., Associate Director for NLM's Health Information Programs Development; Peter Reinecke, former Staff Director for Senator Tom Harkin (D-IA) and consultant to NLM's Office of Communications and Public Liaison; Naomi Miller, Manager, Consumer Health Information in the Public Services Division of NLM; and Patricia Carson, Special Assistant to the Director. Early in the development of the magazine, Kathy Cravedi and Peter Reinecke met with John Burklow and Marin Allen, Ph.D., Associate Director and Deputy Associate Director of the NIH Office of Communications and Public Liaison,

respectively. Together, they agreed to join the NLM and the Friends of the NLM in the production and distribution of *NIH MedlinePlus* magazine.

To publicize the availability of this new resource, on September 20, 2006, the National Institutes of Health (NIH), the National Library of Medicine, and the Friends of the National Library of Medicine joined forces at a joint congressional press conference convened in the U.S. Capitol and attended by lawmakers, their staff, and members of the press [13]. Dr. Lindberg was joined by then NIH Director Elias Zerhouni M.D., who spoke about the new magazine and how it can help to bring good information to the public. Former Senator Tom Harkin (D-IA), the late Congressman Ralph Regula (R-OH), and the late actress Mary Tyler Moore who was featured on the cover of the inaugural issue of the quarterly publication, *NIH MedlinePlus,* also attended.

As described by Lindberg to the media present at the press briefing, "This new NIH publication was developed to provide Americans with a gold standard of reliable, up-to-date health information, including the results of breakthrough research funded through NIH. It was designed to help Americans take control of their own health and better navigate the health care system." The inaugural issue was sent to doctors' offices so patients could learn about NIH and benefit from the information resulting from NIH-sponsored research. (See Photo 3).
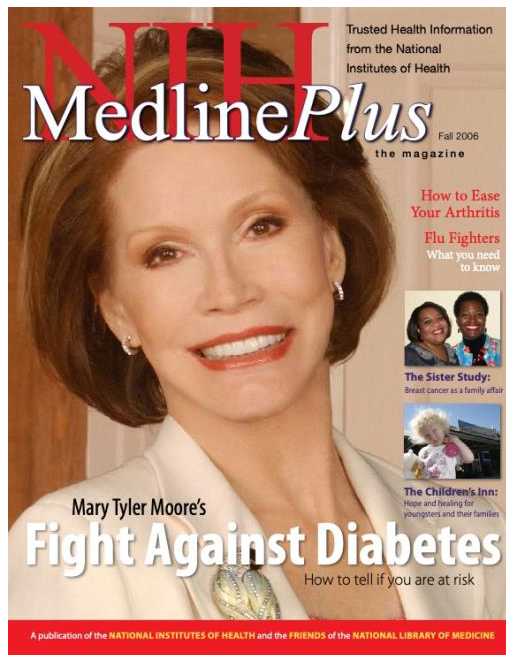
Photo 3. Mary Tyler Moore. Cover image. The NIH MedlinePlus Magazine, Fall, 2006, Friends of the National Library of Medicine.

As it has since its debut, each issue of NIH *MedlinePlus* magazine highlighted several major health conditions, giving readers the most up-to-date and authoritative information on prevention, diagnosis, treatment and research findings. It also shone a spotlight on exciting research currently underway on each condition including on-going clinical trials. *NIH MedlinePlus* armed readers of all ages with the latest information on how to stay healthy for a lifetime. Finally, the magazine profiled some of the most fascinating people – from laboratory scientists to public figures – making a difference in the search for medical breakthroughs. Like its online namesake, *MedlinePlus*, *NIH MedlinePlus* contained no commercial advertising, assuring its readers that the information is produced only for the public good. The magazine was a 32-page, full-color, newsstand-quality publication. Each issue contained one or more special sections dedicated to specific health and disease topics. The NLM published four quarterly issues of the magazine each year. Each magazine focuses on the latest research results, clinical trials, and new or updated guidelines from the various NIH Institutes.

In late 2008 and the fall of 2009, NLM and FNLM created and distributed the first and second issues, respectively, of a free bilingual, consumer health magazine, *NIH MedlinePlus Salud*. NLM partnered on these issues with the National Alliance for Hispanic Health, the nation's oldest and largest network of Hispanic health and human services providers. The dual Spanish/English presentation provided a unique vehicle to reach Hispanics across a wide demographic. The magazine also showcased the many Hispanic-outreach efforts and research-funded results from the NIH's 27 Institutes and Centers.

All of these efforts stem from a mandate by the U.S. Congress to have NIH and NIH-funded research made clear and available to the American people through accessible, informative, and useful educational vehicles. *NIH MedlinePlus* and *NIH MedlinePlus Salud*, in both print and electronic formats, are unique, public-facing information platforms that educate the American people about the NIH's mission, goals, and research results.

To distribute the magazines, NLM secured access to mailing and distribution lists of all U.S. physicians, hospitals, and other healthcare providers. This allowed the magazines to be sent to healthcare providers across the nation for use by their patients in waiting rooms at the point of care. Depending on health conditions featured in individual issues, distribution was customized to reach or target physicians specializing in those conditions to better reach patients interested in obtaining the latest research on their particular health concern.

Distribution totals grew from approximately 40,000 copies for the first issue of *NIH MedlinePlus* in 2006 to between 250,000 and 500,000 copies for issues that followed. Copies of each issue were sent to physician offices nationwide, to NLM's National Network of Libraries of Medicine, to community health centers across the United States, to the media, to the NIH community, the Congress, and individual subscribers. Topics relating to every NIH center of research have been covered in the published issues of *NIH MedlinePlus* and *NIH MedlinePlus Salud* combined. Single-copy and bulk subscriptions to the two magazines were available upon request.

NIH MedlinePlus magazine has been the recipient of numerous NIH Plain Language Awards, as well as an APEX Award for Publication Excellence.

Today, the magazine is freely available online - reaching Americans in both their doctor's office as well as in their homes or anywhere worldwide. NLM is continually pioneering the use of social media platforms to promote the magazine and increase public access to NIH cutting-edge research. As an early adopter of social media, the NLM is

recognized as a "powerhouse" in reaching and helping consumers find good sources of unbiased health information online.

6. Conclusion

Under his leadership, Dr. Lindberg greatly expanded the scope and mission of the National Library of Medicine. Today, NLM and its network of more than 8,000 academic, hospital, and public libraries partner with community-based organizations to bring high-quality information to health professionals and the public-regardless of location, socioeconomic status or access to computers and telecommunications. NLM has entered longstanding and successful partnerships with minority-serving institutions, tribal and community-based organizations, and the public health community. NLM's marvelous exhibitions, discussed in greater detail elsewhere in this book, expand NLM's reach with electronic and traveling versions, bringing important issues and scholarship to persons unable to make it through NLM's Bethesda doors [14].

At his direction, the National Library of Medicine embraced the Internet, enabling the public, health providers, and scientists to gain new or improved access to medical literature via PubMed and PubMed Central; clinical trials and their results via ClinicalTrials.gov; and consumer health information via MedlinePlus and the NIH MedlinePlus magazine. These advances did not always come easy when public policy and other impediments sometimes needed to be overcome, as detailed elsewhere in this book [15].

In his effort to improve patient outcomes, Dr. Lindberg revolutionized the Library's outreach capabilities and successfully expanded its mission to serve not only health professionals and scientists, but also consumers nationwide.

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Environmental Health Information Partnership (EnHIP): Strengthening the Capacity of Minority Serving Institutions

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Abstract. The U.S. National Library of Medicine's (NLM) Environmental Health Information Partnership (EnHIP) collaborates with Historically Black Colleges and Universities (HBCUs) and other minority-serving academic institutions to enhance their capacity to reduce health disparities through the access, use, and delivery of environmental health information on their campuses and in their communities. The partnership began in 1991 as the Toxicology Information Outreach Panel (TIOP) pilot project, and through successive iterations it is NLM's longest running outreach activity. EnHIP's continued relevance today as an information outreach and training program testifies to the prescience of NLM director, Donald A.B. Lindberg M.D's initial support for the program. Dr. Lindberg's seeing to its continued success to benefit participating institutions and help achieve the societal goals of environmental justice serve as well to benefit NLM by increasing its visibility, and use of its resources in the classroom, for research, and in community outreach. NLM envisions an expanding role for EnHIP in advancing health equity as the impact of environmental exposure, climate change, and increasing zoonotic diseases disproportionately impact their communities

Keywords. U.S. National Library of Medicine, Donald A.B. Lindberg M.D., Environmental Health Information Partnership, Historical Black Colleges and Universities, Health Disparities, Environmental Justice, Outreach.

In Memory of Melvin L. Spann Ph.D., 1941-2019.
Director, Specialized Information Services, U.S. National Library of Medicine

1. Introduction

The U.S. National Library of Medicine's (NLM) Environmental Health Information Partnership (EnHIP) is a collaboration between NLM and Historically Black Colleges and Universities (HBCUs), a Predominately Black Institution (PBI), Hispanic-Serving Institutions (HSIs), Tribal Colleges and Universities (TCUs), an Alaska Native-Serving Institution, and a community college. EnHIP evolved from the Toxicology Information Outreach Panel (TIOP) which was established in 1991 as a pilot project in response to the pressing issue of toxic waste and the exposure of toxic chemicals in minority communities. Its mission is to enhance the capacity of minority-serving academic

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institutions to reduce health disparities through the access, use, and delivery of environmental health information on their campuses and in their communities.

EnHIP's beginning can be traced to 1966 at a time of increased concern over the potential effects of environmental chemicals on peoples' health. The U.S. President's Science Advisory Committee (PSAC) examined the state of information in the growing science of toxicology and concluded that "there exists an urgent need for a much more coordinated and more complete computer-based file of toxicological information than any currently available and, further, that access to this file must be more generally available to all those legitimately needing such information" [1]. That recommendation led to the establishment of the Toxicology Information Program at the U.S. National Library of Medicine (NLM).

Further, in 1988, a U.S. Senate Appropriations Committee amendment to NLM's funding authorization mandated that NLM's mission be expanded "…to reach all American health professionals, wherever located, so that they will be able to take advantage of the library's information services." In response to this directive, a 1989 NLM planning panel chaired by Michael E. DeBakey M.D. developed recommendations to guide the library's development of a Library-wide outreach program to improve access to NLM's information resources and take advantage of newly emerging information and computer technologies [2]. The Toxicology Information Program was a model for the extensive outreach initiatives that would follow. In subsequent iterations, it would become NLM's longest-standing outreach program.

In 1991, Charles Walker Ph.D. stepped down from his position as Chancellor of the University of Arkansas at Pine Bluff, an historically Black University. NLM director, Donald A.B. Lindberg M.D. recognized this as an opportunity and invited Dr. Walker to lead NLM's newly created Office of Outreach Development within the Office of Health Information Programs Development. Dr. Walker was keenly interested in connecting underserved health professionals - many of whom practiced in rural and inner-city minority communities - to the library's electronic medical information resources. His initial focus was on the Lower Mississippi Delta region, one of the poorest areas of the nation.

Dr. Walker soon collaborated with Melvin Spann Ph.D., then Chief of the Biomedical Information Services Branch, Division of Specialized Information Services, to create a new outreach project centered around the Toxicology Information Program and a group of Historically Black Colleges and Universities (HBCUs). In just a year's time, NLM lost Dr. Walker who's untimely passing greatly saddened all with whom he worked [3].

Drs. Spann and Walker championed the need for the training of minority health professionals in the use of NLM's electronic information resources. With Dr. Lindberg's strong encouragement and advice, a pilot project was launched, and a select group of senior advisers and stakeholders was convened as the first meeting of the Toxicology Information Outreach Panel (TIOP) in August 1991.

2. Toxicology Information Outreach Panel (TIOP) Aligns with HBCUs

Drs. Lindberg, Spann and Walker recognized that NLM could play an important role in improving the health of minority communities most affected by exposure to toxic chemicals through improving access to the library's information resources by health professionals serving those communities. An obvious way to do this was to work with

the Historically Black Colleges and Universities (HBCUs) who graduate health professionals and other individuals taking leadership positions in these communities.

HBCUs were created by the enactment of the Second Morrill Act in 1890. The Act required states with racially segregated public higher education systems to provide a land-grant institution for black students whenever a land-grant institution was established and restricted to white students. The Higher Education Act of 1965, as amended, defines an HBCU as: "…any historically black college or university that was established prior to 1964, whose principal mission was, and is, the education of black Americans, and that is accredited by a nationally recognized accrediting agency."

Why are HBCUs important for this effort? According to a 1991 document by the U.S. Department of Education's Office for Civil Rights, the two oldest HBCU medical schools, Meharry Medical College and Howard University, have combined to produce over 80% of African American doctors and dentists practicing in the United States at that time [4]. It would not be until 1966, shortly after the Civil Rights Act, that African Americans were admitted into all U.S. medical schools. HBCUs have been successful in premedical education as well [5].

When the Toxicology Information Outreach Panel (TIOP) started as a pilot project in 1991, it included senior representatives from eight HBCUs and a minority-serving educational institution. (Charles Drew University of Medicine and Science is technically not an HBCU since it was started in 1966.)

- Charles R. Drew University of Medicine and Science, Los Angeles, CA
- Florida A&M University, Tallahassee, FL
- Howard University, Washington, DC
- Meharry Medical College, Nashville, TN
- Morehouse School of Medicine, Atlanta, GA
- Texas Southern University, Houston, TX
- Tuskegee University, Tuskegee, AL
- University of Arkansas at Pine Bluff, Pine Bluff, AR
- Xavier University, New Orleans, LA

These institutions included four medical schools, a veterinary school, and nursing and graduate programs. Each institution on the Panel was represented by a Dean, Department Chair, or other senior faculty member. Dr. Bailus Walker, then at the University of Oklahoma, was appointed chair of the panel by Dr. Lindberg. Dr. Bailus Walker was a well-known scientist with research interests in lead toxicity and environmental carcinogenesis. In addition to the HBCUs, participants included representation from other government agencies including the U.S. Agency for Toxic Substances and Disease Registry (ATSDR), U.S. Environmental Protection Agency, U.S. National Institute of Occupational Safety and Health, U.S. National Science Foundation, and several consultants.

2.1. Training

The main charge to TIOP was to develop strategies to strengthen the capacity of HBCUs to use the toxicological, environmental, and occupational information resources developed by NLM. Each participating institution received a customized personal computer (PC) workstation along with specially designed tutorial programs, and free

access to NLM's databases. It is worth noting that in 1991, PCs were not ubiquitous as they are now and were quite expensive. Indeed, a few of the schools reported that these workstations might have been the first ones in their departments on campus. NLM also provided extensive and repeated training in the use of its online databases. Between the in-person training and the customized tutorials, this was intended to be a train-the-trainer program where NLM would provide training to faculty who would then incorporate this into their courses.

This program was seen as so worthwhile that both ATSDR and EPA provided funding to NLM to expand the training program to include over 80 additional HBCUs not part of TIOP [6]. Dr. Charles Walker was instrumental in gaining support from ATSDR.

The HBCU participants at this first meeting of TIOP made many points and recommendations that would become the basis for the project as it continued after the one-year pilot. The most important item in the early stages of this project was the ongoing training provided by NLM and staff from the Oak Ridge Institute for Science and Education (ORISE) located at the U.S. Department of Energy's facility in Tennessee. It was primarily the ORISE staff who, over time, traveled to each of the HBUCs to conduct the actual training sessions. Only by bringing the HBCUs into an understanding of the utility of the NLM online databases was it possible for faculty to begin to incorporate them into their classes and their research. It is important to remember that this was at a time when online searching was not user-friendly and personal computers were expensive and not in widespread use. The panel was also prescient in their recommendation that NLM implement a funding program for these institutions and create an electronic means for networking among the representatives. These activities came much later.

NLM found that this pilot project was sufficiently successful that is should be continued, and the training expanded to additional HBCUs. The panel met at least annually at NLM with Dr. Lindberg in attendance at each meeting. The NLM director's presence and active participation made it clear to the panel members that NLM viewed this as a significant undertaking.

2.2. Growth and Development

In 1997 the decision was made to add representation from Hampton University, Hampton, VA, to TIOP. Hampton has a strong nursing program as well as experience working with their community through the Environmental Justice Information Center. Several years later, in 2001, the TIOP expanded to include institutions serving other minorities, since these populations also experience disparities in health and toxic environmental exposures. The Oglala Lakota Tribal College and the University of Puerto Rico Medical Sciences Campus were added to TIOP. Oglala Lakota College (OLC) was one of the first tribally controlled colleges in the United States. The concept of a tribally controlled college is that it be sanctioned by an Indian tribe, be governed by an Indian tribe, its governing body be made up of tribal members, and that it meets the needs of reservation people in their pursuit of higher education. The OLC nursing program supplies nursing health care providers to the rural and Pine Ridge/Rosebud Indian reservation areas of the northern plains.

2.3. Assessment

2001 marked the tenth year of this pilot project. It was an appropriate time to review of the program and to provide a basis for whether and how to continue. John Scott, director of the Center for Public Service Communications and an NLM consultant, was commissioned to carry out the review [7].

During individual interviews, the panel members offered a long list of the different ways TIOP had an impact on their institutions including supporting the creation of various graduate programs and libraries and promoting the implementation of Internet access for the campus. Several of the TIOP representatives reported that by providing connectivity and computers, this project opened up NLM's databases directly to the faculty and students. Prior access was either too expensive or only available through the librarian, which was a good service but did limit access and exploration.

The consensus was that TIOP did fulfill its goal to increase awareness and use of NLM's databases at the participating institutions. But the TIOP representatives felt that they could do more to help NLM as well as benefit their own institutions. They recommended modifying the program objectives to include health disparities, to broaden representation with additional minority serving institutions, and to increase the interaction between the institutions and NLM. A new mission statement was proposed at the 2003 meeting: "The mission of the Environmental Health Information Outreach Panel is to enhance the capacity of minority-serving academic institutions to reduce health disparities through the access, use, and delivery of environmental health information on their campuses and in their communities."

In response to the assessment and with the support of Dr. Lindberg, NLM and TIOP made several additional changes to the program. Clearly, this was no longer a pilot project; it was an ongoing program of the National Library of Medicine.

Regarding staffing, Gale Dutcher assisted Dr. Spann with TIOP, and when he retired in 1999, she assumed responsibility for direction and oversight of TIOP/EnHIP in her role as head of the SIS's Office of Outreach and Special Populations. She was assisted by Cynthia Gaines, the EnHIP project officer, who managed the process of organizing the meetings. John Scott, an outside consultant, advised NLM staff and Panel leadership. Scott brought considerable expertise in minority health and community outreach to EnHIP, as well as to other important outreach initiatives undertaken NLM-wide.

3. Environmental Health Information Outreach Program (EnHIOP)

In 2004, the Panel evolved from TIOP to Environmental Health Information Outreach Program (EnHIOP) to reflect what was now a wider outreach program as more schools were added to the program in order to reflect more diversity in participating institutions [8]. The group established some long-term goals to guide the program into the future. These goals included further institutionalizing NLM resources, strengthening institutional partnerships with libraries and other information centers, boosting and developing community-based and faith-based organizations to extend health-related outreach to communities surrounding participating institutions, and increasing participation within the schools through professional meetings, presentations, and panel discussions.

Dr. Lindberg commended the group for its perseverance and sense of mission that had made it possible for the program to last for 10 years, stating that this was a remarkable accomplishment that demonstrated a commitment to paying attention to underserved populations. He also offered several recommendations to the panel including budgeting sufficient time to know each other and work together; understanding the history and laws of the participating institutions and their current needs; consider extending the EnHIOP meetings beyond one day to allow presentations on new topics and by external experts; sharing best practices - with each other and with NIH; identifying high priority opportunities and writing proposals to explore them. He reminded them that although NLM itself can act only upon those things the institution is entitled to act upon, it can also be a conduit to other agencies and other parts of the U.S. National Institutes of Health (NIH) that are also committed to these goals. He emphasized the importance of toxicology and environmental health to NIH and its relationship to other topics of interest.

EnHIOP and NLM staff determined that two ways to respond to Dr. Lindberg's comments were to increase the number of meetings to two per year and hold one of those meetings at one of the institutions participating in EnHIOP. This would allow the participants to gain a better understanding of the various institutions and foster more participation by faculty at those institutions and their local communities. Further, the group determined that it would be important to tie the work of EnHIOP to NLM's Long Range Plan.

4. Environmental Health Information Partnership (EnHIP)

As more institutions joined the program, its name was changed in 2009 to Environmental Health Information Partnership (EnHIP) which defined the program's true status as a partnership between NLM and leading educational institutions. The Partnership now reflects a broader focus on the multicultural dimensions of environmental health, environmental health sciences, and health disparities.

5. Moving from Campus to Community

Based on Dr. Lindberg's advice and internal discussions, NLM committed to funding small outreach projects for EnHIOP/EnHIP member institutions. HBCUs and other minority serving educational institutions are of critical importance to their surrounding communities. HBCUs have traditionally played a key role in the education of African Americans, and tribal colleges and Hispanic serving educational institutions play parallel roles for their respective constituency groups. Graduates of these institutions often play leadership roles in their communities. Further, the institutions themselves, students, and faculty are involved in a wide variety of local community outreach working to better their geographic areas. As NLM began to play a greater role in providing consumer health information, it was clear that the EnHIOP institutions could play a significant role in developing diverse model community outreach programs. Therefore, starting in 2005, NLM made small awards of $5,000 to EnHIOP participating institutions for local community health information outreach projects. The most recent awards were made in 2018.

6. Review of EnHIP

To validate the impact and continued relevance of EnHIP and to help guide the Partnership in the future, NLM, with assistance from Oak Ridge Associated Universities, conducted a needs assessment in 2015–2016. The review found that the EnHIP representatives used NLM resources and their participation in the Partnership to improve environmental courses at their institutions and they included this information and their involvement with NLM in grant submissions. They shared their information with faculty and staff at their institutions and presented it at lectures and outreach activities. Representatives also mentioned the benefits of networking and collaboration among member institutions and enhancing their institutions' capacity to conduct research and publish on health issues for minority and underserved populations. While it was clear that the institutions benefited from their participation in EnHIP, NLM also benefited by its increased visibility at these minority serving institutions and increased use of its resources in the classroom, for research, and in community outreach projects.

7. Continuing Importance of the Environmental Health Information Partnership

TIOP was started because of the recognition of the profound impact of environmental exposure to toxic substances on minority communities. A number of protests and publications in the 1980's brought the issue of environmental racism to the public's awareness. "This is environmental racism: How a protest in a North Carolina farming town sparked a national movement", by Darryl Fears and Brady Dennis writing for the Washington *Post* on April 6, 2021, clearly shows how one of the most significant incidents started the environmental justice movement [9]. Similarly, a seminal 1987 study by the United Church of Christ, "A National Report on the Racial and Socio-Economic Characteristics of Communities with Hazardous Waste Sites" documented the relationship between the placement of toxic waste dumps and race and economic conditions [10]. It clearly shows that race rather than economic level was most important in the siting of toxic waste dumps. Work on toxicology, environmental health and health disparities continues to be quite relevant. It is more than unfortunate the UCC's updated study, "Toxic Wastes and Race at Twenty 1987-2007" suggests there is still a great need for work in this area [11]. This report found that racial disparities in the location of toxic waste facilities were "greater than previously reported People of color comprised most of the population in communities within 1.8 miles of a facility." This certainly testifies to the continued relevance of EnHIP and the importance of the availability of toxicology and environmental health information.

7.1. A Look to the Future

NLM is continuing to support and work with EnHIP. In addition to regular meetings, NLM makes awards for community information outreach projects. A virtual meeting was held in 2020 due to COVID-19, the main topic revolved around the global pandemic. The institutions participating in EnHIP are well positioned to engage with their communities to hear their concerns and ensure that they are getting the most up-to-date health and medical information about COVID-19 transmission, treatment, and prevention. It is important that minority communities which are the most seriously impacted by the disease, can access accurate information from trusted sources. EnHIP

institutions are such trusted sources and can help to combat a lot of the misinformation being shared person to person and by social media. There is an ongoing role for EnHIP, perhaps even an expanding role in advancing health equity as the impact of environmental exposure, climate change, and increasing zoonotic diseases disproportionately impact their communities.

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HIV/AIDS Community Information Outreach Program (ACIOP): A Landmark NIH Conference and an Enduring NLM Role in Meeting the Affected Community's Need for Information Access

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Abstract. In June 1993, the National Library of Medicine (NLM) joined with the National Institutes of Health's (NIH) Office of AIDS Research (OAR), and the National Institute of Allergy and Infectious Diseases (NIAID) to host a conference at a pivotal time in the HIV/AIDS epidemic to understand better the information needs of five major constituency groups: clinical researchers; clinical providers; news media and the public; patients; and the affected community. NLM's director, Donald A.B. Lindberg M.D., and staff sought to identify new program possibilities benefitting from the input of current and potential users of the Library's information services. Conference recommendations led to a key NLM policy change providing cost-free access to all AIDS data, and the establishment of the HIV/AIDS Community Information Outreach Program (ACIOP), which enabled new partnerships with local community-based organizations serving the affected community. Uniquely funded and long running, more than 300 ACIOP projects have been supported to-date. These projects have improved awareness and use of national HIV/AIDS information resources; enhanced information seeking skills; developed locally generated information resources; and enhanced the capacity of community-based organizations to use new information and computer technologies providing access to essential information resources and services.

Keywords. Donald A.B. Lindberg M.D., U.S. National Library of Medicine, U.S. National Institutes of Health, HIV/AIDS Community Information Outreach Program, HIV/AIDS Information Services Conference, Community-Based Outreach

1. Introduction

The first cases of what would later become known as Acquired Immunodeficiency Syndrome (AIDS) were reported in the United States by the Centers for Disease Control in June 1981 [1]. This was quickly followed by reports of previously healthy young homosexual men becoming infected with *Pneumocystis pneumonia*, a type of pneumonia that almost never affects people with intact immune systems, as well as Kaposi's Sarcoma, usually found in older men in Mediterranean countries [2].

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1.1. Early Responses

The primary communities affected by what would become known as the AIDS pandemic were gay white men and Haitians. While this changed and broadened over time, AIDS' initial impact on marginalized communities was accompanied by a highly negative public response. The initial name for this disease was GRID – gay-related immunologic syndrome. Along with an initially high mortality, it was characterized by homophobia, discrimination, and stigma against those diagnosed with the disease.

There continued to be widespread fear and hostility to people with AIDS and the Human Immunodeficiency Virus (HIV) that causes AIDS which drove the political and social responses to this disease. With mainstream medical, social and human services organizations so fearful and reluctant to provide care and support services to people living with HIV and AIDS, the communities most impacted created organizations to take care of their own members. These community-based AIDS service organizations were founded to support and care for people with AIDS primarily because of homophobia and distrust of the government and public health agencies as well as the slowness of these agencies to respond to what was seen as a crisis from within the affected community. They also served as advocates for these communities.

2. National Library of Medicine's (NLM) Involvement in AIDS

Information about AIDS, HIV, research, transmission, and care became critically important. The Health Omnibus Programs Extension (HOPE) Act of 1988 (PL 100-607) included a section that provided funding for AIDS-related education, prevention, research, and testing. The National Library of Medicine (NLM) was prescient in its creation of bibliographic tools related to AIDS. Initially it created printed bibliographies and then AIDSLINE, an online database. Donald A.B. Lindberg M.D., Director of the National Library of Medicine made the official determination that this satisfied the legislative requirement to establish a "data bank of information on the results of AIDS research."

The urgency of the situation led to significantly increased funding to the National Institutes of Health (NIH) specifically targeting work relating to the AIDS pandemic. The NIH Office of AIDS Research (OAR) was responsible for the allocations to each institute for their AIDS-related activities. Dr. Lindberg was very firm that he only wanted NLM to accept the additional funding if there were worthwhile new programs NLM could do that would add to the improvement of the situation and solicited input from staff for their ideas. Besides continuing and expanding NLM's traditional role of collecting books and journals, indexing the research literature, and making AIDSLINE and other databases available, Dr. Lindberg and Library staff determined that it needed more input from users and potential users to understand their information needs.

3. HIV/AIDS Information Services Conference

To obtain this information from the full gamut of users and potential users, NLM collaborated with the NIH's OAR and the National Institute of Allergy and Infectious Diseases (NIAID) to hold a conference on behalf of NIH to identify the information

needs of relevant constituent groups. The planning committee was chaired by Elliot R. Siegel Ph.D., NLM Associate Director for Health Information Programs Development, and consisted also of representatives from external organizations such as the National Association of People with AIDS, community-based organizations, public health agencies, and NIH staff. Gale A. Dutcher MS MLS, Special Assistant to the NLM Associate Director, Division of Specialized Information Services assumed day-to-day responsibility for organizing the conference.

The first step was to identify the potential audiences for NIH's information. Initially they were Basic science researchers, Clinical researchers, Clinical care providers, General public, and Community-based organizations (CBOs). Preliminary research, including interviews with basic scientists, led to the elimination of basic scientists from the conference agenda as the feedback that was received showed that they had sufficient institutional access to the information they needed to advance their work. This was the type of information that NLM had been effectively providing for over 150 years.

The NLM/NIH HIV/AIDS Information Services Conference took place in June 1993. It was organized around the HIV/AIDS information needs of five major constituency groups: clinical researchers; medical, dental, and nursing providers; allied health care providers; news media and the public; and patients and the affected community [3].

Keynote addresses by Dr. Lindberg; Anthony Fauci M.D., Director, National Institute of Allergy, and Infectious Diseases; June Osborne M.D., Chair, National Commission on AIDS; and Debra Frazer-Howze, Black Leadership Commission on AIDS provided big-picture perspectives to the constituency group panels and the audience. Each panel represented a specific constituency group and was given a scenario to guide their discussion. The result of the panel discussions and audience participation was more than 40 recommendations to NIH related to information needs and access.

The planning group as well as the conference participants were diverse and included good representation from all those impacted by AIDS –researchers, policy makers, information providers, as the affected community. It was the first opportunity for many NLM staff to work with people infected with HIV or who were active in that community. While Dr. Lindberg was not at all concerned by this, some of the NLM staff were worried about seating arrangements and being close to someone who might be infected.

3.1. Major Conference Recommendations

The panel discussions resulted in a large number of recommendations that would help meet the needs of the various constituency groups.

The clinical researchers' recommendations centered around immediate access to the results of clinical trials regardless of where they were being conducted, and increased transparency of the most current information from important conferences. They also recommended more information for patients and health consumers.

Medical, dental, and nursing providers obtain their information through differing routes than the clinical researchers and they may not have the time, access, or expertise to obtain and synthesize reports from the scientific literature. They sought synthesized, integrated information to directly support patient care. The lack of access to information was most profound for practitioners working in more remote areas.

Allied healthcare providers, including case managers, social workers, nutritionists, and various types of therapists, are often the provider most frequently seen by people

with AIDS or HIV. They work in various settings and may not be based in a resource-rich institution such as a medical center. Their needs were clearly related to access to existing systems for information dissemination and the availability of the type of information they can use – relevant topics, particularly substance use, psychosocial issues, and alternative treatment, and at the appropriate technical level.

The media are the main conduit that NIH used to transmit information to the general public. However, a surprising finding was that the media does not see its primary role as educational. They did emphasize their need to have better access to the scientists to obtain the information needed for their reporting. The panel also encouraged NIH to use other mechanisms to reach the public and not rely only on traditional media.

The importance of accurate and current information is critical for patients and the affected community. Because of the stigma, prejudice and discrimination shown to people with HIV and AIDS, this group organized to take care of themselves and their own community. They wanted accurate information available where they spent time and in formats that were useful. They wanted it to be available to their care providers as well as to the affected community. Electronic information services, which were seen to have the potential to get information out to the community quickly, were not readily available for many different reasons, including cost, complexity, and access to technology.

3.2. NLM's Initial Response: Cost Free Access

In January 1994, Dr. Lindberg took the major step of announcing that NLM's AIDS-related databases were available to all free of charge [4]. This was responsive to recommendations from several of the panels and would be of assistance to health professionals not affiliated with institutions providing access to NLM's resources. It would particularly help community-based organizations providing services to the affected community. This was the first time that NLM made its databases available free of charge to anyone who registered and obtained an access code. Although the pre-web search system in use at that time was complex, it did provide access to those who otherwise would not be able to afford to use the most up-to-date information available through NLM. Beyond this, providing free access gave NLM experience with opening access, which took place in 1997.

4. New NLM Initiative Launched: HIV/AIDS Community Information Outreach Program (ACIOP)

It was clear from the conference discussions that people with and affected by HIV/AIDS wanted access to timely and accurate information. It was also clear that many members of this group and the community-based AIDS service organizations that had arisen in the earliest years of the AIDS epidemic did not have access to or the ability to access electronic information resources.

To provide support to these organizations, NLM issued a request for proposals (RFP) for AIDS Community Information Outreach Projects in May of 1994. This was NLM's first significant outreach program for community organizations. The goals of this competitive funding opportunity were to support access to and the use of quality relevant information, including training, equipment, and connectivity. Further, the conference

recommended that the public library system be utilized to provide assistance in getting accurate, timely information to the public.

In what turned out to be the first of many annual rounds of funding, a total of nearly $500,000 was awarded to 19 projects. The goal was to improve access to HIV/AIDS information for health professionals, patients, the affected community, caregivers, and the general public; encourage partnerships and community-focused activities; and promote awareness and use of technology applications for improved information access. The selected projects addressed one or more of the following:

- providing or improving access to electronic HIV/ AIDS-related information resources by organizations or by the clients they serve, including the purchase of equipment and telecommunications services and creating a computer facility in a CBO.
- providing or obtaining training to develop skills to access or use HIV/AIDS-related information, including using the Internet and critical assessment of the quality of retrieved information.
- developing specific educational or information materials, such as culturally appropriate or language specific tools.
- providing access to HIV/AIDS-related documents, for example, developing connections with local health sciences libraries to obtain use of their collections.

NLM designed the AIDS Community Outreach Program to improve access to HIV/AIDS-related information by CBOs, public libraries, people living with and affected by HIV/AIDS, and the public. In response to guidance from its constituents in the HIV/AIDS service community, NLM's role has been to specify the program objectives and the types of activities it would support. It respected the community's expertise in designing and proposing projects most likely to be effective in their communities. NLM's supportive role has fostered the development of projects that are "owned" by their communities, and helped to create productive working relationships between NLM and information providers.

4.1. ACIOP Over Time

The first group of institutions receiving awards was diverse. It included community organizations (e.g., Critical Path AIDS Project, Santa Cruz AIDS Project), departments of health (e.g., Seattle-King County Department of Public Health), libraries (e.g., Kansas City Public Library), and academic institutions (e.g., Eastern Virginia Medical School) [5].

The early projects that NLM funded generally focused on basic services. Few of the organizations or their clients were in a position to use advanced technology. For example, the New York Public Library projects (1994,1996) expanded branch and reference library collections to include HIV/AIDS educational materials. The NYPL-Staten Island project (1994) acquired books in both English and Spanish, pamphlets from a variety of sources, videos, and newsletters and magazines. AEGIS (1995) was one of the first projects to use the web. Prior to NLM funding they ran a dial-up BBS (bulletin board) service over telephone lines. They migrated to a listserv with the funding. The growing demand for listservs suggests that email was increasingly available to consumers of HIV/AIDS information. AEGIS (1995) reports that its FTP server "isn't used much

because of the Web, except by people from very remote sites with limited tech use...who download info and recreate databases in their countries." According to AEGIS (1995), the "Web has changed everything."

Several projects received funding over multiple years. One notable example was Philadelphia Fight. Two components of that organization received funding in 1994 – Critical Path AIDS and the AIDS Information Network (AIDS Library). They or another component of Philadelphia FIGHT received funding in many of the following years. An expansion of the AIDS Library and the Critical Path Project, the Critical Path Learning Center at Philadelphia FIGHT is an educational commons and stigma-free space devoted to the intersection of health and literacy for the digital age, received funding. They made information access central to their mission. Over the years, NLM funded the AIDS Library to set up computers for public access in their facility, an educational program called Project TEACH, and the Critical Path Project to develop electronic resources and websites.

Over time, the demographics of those most affected by HIV/AIDS changed from predominately gay White men to communities of color, including both men and women. This led to changes in the organizations receiving funding and the populations they served. In addition, the later projects took advantage of newer technology, including sophisticated use of social media, audio and video to develop locally or population-relevant resources. HIV PrEP Navigator resources and dissemination strategy development was also supported and included tailored web-based videos and educational modules, text messages or email messaging campaigns, as well as culturally and language specific fact sheets, and user guides tailored to meet the needs of the organization's clients or communities.

Another example is Black Girl Health which helps minority women make informed decisions about their health. They run a national social media campaign using Facebook and Instagram to increase awareness about HIV prevention, specifically pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP). By connecting Black women to the National Library of Medicine (NLM) HIV/AIDS resources, educating them about PEP and PrEP, offering them support, and teaching them how to transfer this knowledge to their own self-care, Black Girl Health educates African American women to make better informed decisions regarding their health. BGH also collaborated with NLM to develope a YouTube video highlighting the 2016 awardees whose projects incorporated the use of new information technologies [6].

5. Successive Evaluations of the ACIOP

This program is more than 25 years old and has undergone periodic reviews, assessments and formal evaluations during that time period, which has led to modifications of the program to keep it useful, relevant and impactful.

The first review of NLM's program covered 1994-1997 (unpublished internal document). It was essential to conduct this early review since the program was so new and different from anything that NLM had done previously. This unpublished review examined the reported accomplishments of the projects. It found that they could be grouped as follows:

- Awareness and Use of HIV/AIDS Information Resources

   o Improving Access to Educational Materials
   o Improving Access to the Internet
- Improving Information Skills
- Developing New Resources
- Building Organizational Capacity To Provide Information Services
   o Developing Computer Infrastructure
   o Fostering Partnerships and Collaborations

NLM learned valuable lessons from this first set of projects which could then be applied to future program efforts. The staff of community-based organizations required a great deal of training to learn how to use electronic resources and to incorporate this information into their daily tasks. This was very early in the Internet era and staff were not using the Internet or telecommunications in their daily lives. Although public library staff were more accustomed to searching for information, they required extensive training in searching NLM's databases and in accessing and searching the Internet before they were prepared to assist the public. One of the most important findings was that community-based organizations required more than one funding period to reach the point of providing direct access to electronic resources for their clients, or to otherwise bring their projects to a satisfactory point. NLM also recognized the importance of good leadership and in having a champion within the organization. This is critical in community organizations since there is often high staff turnover, extensive use of volunteers, and loss of important staff due to the impact of the disease.

Even during the relatively brief time covered in this review, the epidemic and the Internet changed significantly, and this impacted the community organizations. The Internet and the web became much more widely available and used, the demographics of the affected community shifted with increasing numbers of minority and lower income individuals becoming infected, and finally, there was an increasing need for more information about general health as people started living longer.

A later look at the program showed the impact and continued need for funding [7]. Through 2005, NLM made more than 190 awards and incorporated programmatic changes based on reviews and analysis of report submissions from the organizations. For example, the initial funding amount in 1994 was $25,000. Later, funding levels were raised to $50,000 for standard awards and an express category for $10,000 was added which supported smaller scale projects and required reduced application requirements. A qualitative assessment of projects funded in 2002 (most of which were carried out over a 2-year period) found that increased access, use and knowledge of HIV information significantly impacted the clients' communication, improving their ability to ask knowledgeable questions. For many of the organizations, making technology and access to HIV information available in disadvantaged communities filled a significant gap in those areas and provided information and tools that would otherwise not be available. It also extended the reach of the organization beyond their immediate community. Anecdotes from users of some of these services have credited that the access provided was "keeping them alive."

This assessment repeated the findings of the earlier review that a strong, committed project leader was an essential component for success. Further, the staff turnover, particularly in the smaller community-based organizations, was also a problem in managing projects and resulting in the loss of institutional memory and knowledge.

In 2012, a major external program evaluation was undertaken to determine the performance and impact of the AIDS Community Information Outreach Program (ACIOP). This systematic and detailed analysis was carried out by researchers from Columbia University in conjunction with the ACIOP staff at NLM [8].

It was important to review the program given the substantial level of resources NLM invested and in recognition of the changing environment over the approximately 20 years of the program. The researchers analyzed a sample of project reports and conducted structured interviews of a number of projects. Since 1994, the Internet and web have become pervasive and more accessible, and social media had become one of the main communication tools, especially among younger people.

This evaluation found that, in general, planned project objectives were achieved and successful projects built on existing efforts. Most of the projects identified barriers to success and found ways to overcome them. Some of these barriers repeated the findings of earlier assessments and reviews, such as staff changes leading to gaps in project management. The most significant problem or barrier identified was the lack of evaluation capacity in community organizations. We found that few community organizations had the staffing or training to know how to evaluate their projects.

One recommendation from this evaluation was that NLM provide more guidance and support to the community organizations to enable them to do more effective evaluations, including needs assessments and developing measurable objectives. NLM carried out a pilot project which involved helping a group of organizations to include evaluation in their ACIOP projects [9]. Based on lessons learned from this pilot, NLM modified the proposal submission and evaluation criteria for funding to include a required logic model so that evaluation planning was considered early in the program development process. NLM was able to determine the evaluation capacity of each proposer prior to award. Post award, NLM supported the organizations with evaluation consultation to ensure that their projects aligned with their logic model. This effort increased the successful implementation and evaluation of ACIOP projects and enhanced the evaluation capacity for low-resource awardees.

6. An Innovative Model for Community-Based Outreach

Initial conception and direction of the ACIOP was under the leadership of Gale Dutcher who later became Chief of the SIS's Office of Outreach and Special Populations. She was followed by her associate Nicole Scott whose very capable management of the ACIOP began in 2007; and Andrew Plumer assumed day-to-day responsibility in 2014. Ms. Scott was instrumental in guiding ACIOP's several transitions, a comprehensive formal evaluation, and an experimental effort at capacity building enabling awardees to undertake their own project evaluations with the assistance of an evaluation consultant provided by NLM.

The ACIOP was a risky and unusual undertaking for an NIH Institute. Funding was provided in the form of targeted small contracts rather than grants as the Intramural administrative status of the NLM's Division of Specialized Information Services is not authorized to award grants. Moreover, the contracts were structured for community organizations that were unlikely to have the staff expertise to compete for standard NIH research grants and were most likely unfamiliar with the federal contracting process. Dr.

Lindberg and NLM staff felt strongly that the critical nature of the AIDS epidemic justified this unusual funding approach.

NLM has funded over 300 ACIOP projects. The periodic reviews have led to program modifications to enhance the program, determine the impact of the ACIOP effort, and ensure ACIOP remains relevant and responsive to current community needs. Project funding has fluctuated over time and reporting has improved, as NLM created more structured reporting and evaluation criteria to determine the impact of the projects. As the epidemic changed and technology became more ubiquitous, the emphasis of the projects also changed, as did the needs of the organizations. One thing remained true throughout the entire time – the importance of meeting the needs of the local community and their local authority of the projects. All in all, using NLM's quality information resources was essential at the local and national level.

ACIOP awardees were community organizations mostly serving minority, disadvantaged or marginalized populations. Over the years, NLM has established partnerships and built relationships with communities where their lack of trust may have inhibited NLM's direct reach and engagement with diverse populations that need HIV information the most. By working with organizations and identifying "ambassadors" and "champions" in communities that have already developed trusted relationships with their clients and community members, NLM has been able to ensure that ALL individuals have access to high quality, accurate and authoritative information in settings that are comfortable for them.

The AIDS Community Information Outreach Program continues to be relevant and beneficial both to the HIV/AIDS community and to NLM. It remains a very important component of NLM's work with communities and community organizations. Lessons learned over time have proven relevant not only to this one program, but to information outreach in general, whether directly from NLM or through the Network of the National Library of Medicine (NNLM) [10]. The success of NLM's community-based outreach can be attributed to Dr Lindberg's leadership and his staff's willingness to break away from what was considered the "normal" established audiences and partnerships as initially identified in the then-groundbreaking 1989 DeBakey Outreach Panel Report [11]. NLM outreach broke new ground and progressed in new directions with the evolution of the AIDS Community Information Outreach Program.

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Mentoring in Medicine (MIM): Motivating and Enabling Disadvantaged Youth to Become the Next Generation of Minority Health Professionals

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Abstract. Mentoring in Medicine, Inc (MIM) is a nonprofit health and science youth development organization based in the Bronx, NY. Founded in 2006 by three physicians and an engineer- trained entrepreneur, MIM's organizational goal is to expose socioeconomically disadvantaged students to the wide variety of health and science careers and to increase the health literacy of their communities. It is aligned with the outreach mission of the U.S. National Library of Medicine (NLM) whose former Director, Donald A.B. Lindberg M.D., fostered an enduring relationship. Technical assistance, evaluation, and financial support provided under his leadership helped MIM to become a nationally recognized organization leading the field to diversify health careers and to increase health literacy in often hard to reach populations. Through live and virtual programming, MIM has impacted nearly 58,000 students, parents, and educators in urban epicenters in the U.S. The MIM Team has helped 503 students who were discouraged to build a competitive application and matriculate in health professional school. MIM has 88 press features highlighting its work in the community.

Keywords. U.S. National Library of Medicine, Donald A.B Lindberg M.D., Mentoring in Medicine, health and science careers, disadvantaged youth, health disparities, outreach.

In memory of Donald West King M.D., 1927-2018
Deputy Director for Research and Education, U.S. National Library of Medicine

1. Introduction

Mentoring in Medicine, Inc. (MIM) is a 501c3 health and science youth development organization based in the Bronx, NY. It was founded in 2006 by three physicians Lynne M. Holden, M.D., Yvette Calderon, M.D., Jocelyn Freeman-Garrick, M.D. and an engineer-trained entrepreneur, Andrew Morrison. The purpose of MIM is to expose socioeconomically disadvantaged students to the breadth of health and science careers, in addition to promoting health literacy in communities in need. MIM is aligned with the

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outreach goals of the U.S. National Library of Medicine NLM), as co-featured by the *NIH MedlinePlus Mag*azine [1].

The mission of MIM is to inspire, educate, expose, and empower young people to pursue their goal of becoming a healthcare professional and adopt a role as a community health ambassador. (See Photo 1.) It is a unique continuity program, the target audience is made up of students from elementary school to health professional school, along with parents and educators. The goal of MIM is to broaden the diversity of the biomedical workforce and to reduce disparities in health care. Using academic enrichment, leadership development, civic engagement, and mentoring, MIM helps students develop the knowledge, attitudes and skills needed to succeed.

Photo 1. At a Mentoring in Medicine event, a possible future healthcare professional gets the chance to model a lab coat with a MIM mentor.

1.1. The Challenge

Mentoring in Medicine was conceived to increase the diversity of health and science careers by expanding the pool of competitive applicants targeting disadvantaged populations in which representation is historically very low. Each of the co-founders had a uniquely difficult path to becoming a physician. However, in making the path easier for young people, it was realized there would be many challenges to the work. Many students are first generation college or even high school graduates not aware of the

journey to a health career. Other students suffer from adverse childhood experiences such as food insecurity, homelessness, and financial instability. Most must work while attending high school or college. Additionally, many students have attended under-resourced middle and high schools without opportunities for academic enrichment necessary to build a strong foundation. Other real obstacles to the program included the creation of culturally appropriate and exciting content to capture the attention of the students to keep them engaged at the middle and high school level.

2. A Pivotal Point for MIM

In 2007, Lynne Holden M.D. and David Nash, Equal Opportunity Officer at the National Library of Medicine (NLM), met during a networking event at the National Medical Association's Annual Conference in Hawaii. Mr. Nash introduced Donald West King, M.D., who served as the Deputy Director of Research and Education at NLM, to Mentoring in Medicine, Inc. during a clinical skills workshop for medical students at the concurrently held Student National Medical Association Conference. Even though he was observing the MIM workshop for medical students, Dr. King jumped right in and began explaining the physiology of the heart during the EKG workshop. He also put on a pair of gloves and began to point out the anatomy of the pig's heart and explain the physiology of the human heart. The MIM Team had no idea that he had been the Chair of Pathology at the University of Colorado, the University of Chicago and Columbia School of Physicians and Surgeons. But they knew that he was an ally!

3. A Breakthrough with the National Library of Medicine

Dr. King referred Dr. Holden to Donald A.B. Lindberg M.D. NLM Director, who after a lengthy competitive vetting process enthusiastically encouraged MIM to collaborate with the American Dental Education Association (ADEA) on a new outreach project that would combine their respective interests in promoting health careers for students. The leaders of both organizations decided to work together on a mutually beneficial effort that would further inform their individual causes. They decided to perform two focus groups in NYC about the perceived obstacles to a health career among urban students, parents, and educators, to learn strategies to effectively promote health careers and to demonstrate a new ADEA online platform. Representatives of both organizations worked together to host the first event over dinner at The New York Academy of Medicine and the second a month later over lunch at Frederick Douglass Academy I in Harlem. Subsequently, a manuscript documented the results that informed the work of MIM [2]. In fact, hosting the focus groups launched one key practice in MIM's success over the years which has been to query the target audience before designing and implementing a program. Therefore, the motto," not me without me" drives the creation of any new MIIM program. Changing norms requires constant surveying of the target population to make sure that their needs are met in an effective manner.

The focus groups yielded important results. The inclusion of parents as key participants in the group was unusual. In total, there were six focus groups studied: with a total of 45 persons in the first session, and 10 persons in each of the second session groups. There were surprising differences between the knowledge, attitude and beliefs

of the students, parents, and educators. Based on the results of the focus group, a clear case was made for the need to introduce students in middle and high school to a variety of health careers so they could be academically competitive, develop social identity and participate in experiential learning opportunities. The strong lack of confidence to pursue health careers that was expressed at multiple educational levels was disheartening but gave the MIM Team clear direction that programs needed to incorporate a growth mindset with engaging activities and clear incentives for excellent performance.

4. Building the Relationship with the National Library of Medicine

Annually, for ten years, MIM hosted a large celebration of health careers. Typically, up to 2,500 students, parents, and educators along with nearly 200 health professionals and health professional students would participate in a day-long Saturday immersion experience showcasing a variety of health careers through pep rallies, hands-on activities, and workshops. Dr. and Mrs. Lindberg traveled to NYC in 2008 and attended the "Yes, I Can be a Healthcare Professional!" Conference in Harlem, New York at the Frederick Douglass Academy I (See Photo 2). After walking around the Exhibit Hall and speaking to students in the New York after school program as they presented health career posters, Dr. Lindberg became an advocate! Once they returned to Bethesda, Dr. Lindberg and Dr. King led the capacity building and replication effort of Mentoring in Medicine together.

Photo 2. Dr. Holden with Dr. and Mrs. Lindberg, center, at the 2008 MIM Conference, "Yes, I Can Be a Healthcare Professional!"

With this new NLM connection, Dr. Holden as MIM president, was invited to join the Board of Directors of the Friends of the National Library of Medicine (FNLM) in

2009. This nonprofit organization supports the mission and strategic plan of the NLM. Under the chairmanship of Dr. King, the FNLM adopted MIM as an outreach arm. Through collaborative projects, MIM strives to increase the workforce diversity by building data literacy and encouraging healthy living in our programs for students from middle school to health professional school.

4.1. The NLM Outreach Team

After his first experience in Harlem, Dr. Lindberg expressed his growing enthusiasm for the work of MIM. He was able to envision the possibilities of the then fledgling nonprofit organization. He invested his resources at the NLM, the world's largest medical library, to help multiply the impact of MIM on the world. What a one in a million chance for an early nonprofit to receive such a gift! Dr. Lindberg developed an Outreach Team to assist with MIM Programs through technical assistance, evaluation, replication, and fund development. The Team consisted of: Patricia Carson, executive assistant to Dr. Lindberg; Elliot R. Siegel Ph.D., Associate Director; George Franklin, outreach leader; and David Nash. Later, Wallace G. Berger, PhD. LightShift Associates, LLC, joined the team as an evaluation consultant. Dr. Lindberg charged Dr. King with leading the direction of the Outreach Team.

5. The Growth of MIM

A key factor in the growth of MIM was the technical assistance provided by the Outreach Team. Dr. King invited Dr. Holden and the MIM leadership team to his home in Riverdale to assist with the middle and high school program development to incorporate pathobiology, a term that Dr. King coined, in 1967 when he co-founded the Givens Institute of Pathology in Aspen, Colorado. The weekly technical assistance sessions occurred every Wednesday evening after the family (and friends) dinner for 11 years. These sessions led to the development of the first Anatomy, Physiology, Pathology and Biomedical Careers Elective in NYC high schools, an after-school program (ASP) for middle school students, and a summer camp for middle and high school students [3]. The MIM school-based programs incorporated engaging project-based learning using NLM information resources such as the NIH Medline Plus Magazine, the MedlinePlus consumer health website, and the PubMed biomedical literature citation database.

5.1. After-School Program

The MIM After-School Program (ASP) has as its primary objective to provide academic enrichment in human biology and to motivate disadvantaged youth to pursue a career in the health professions. Secondary objectives are to improve students' health literacy and knowledge of healthy living behaviors. A qualitative and quantitative study was performed on the ASP in six schools with 84 students in 9th-12th grades who completed the 10-week semester [4]. Students across the academic spectrum appeared to have learned the MIM ASP Course content - high school GPA was not a predictor of knowledge acquisition. The students also reported that the ASP Course significantly increased their self-confidence in their ability to succeed (self-efficacy). The students expressed a significant increase in five health care related attitudes and an additional

increase in their ability to overcome personal issues to succeed in their career and significantly improving their feeling toward, and likely pursuit of, a health career. The students stated that the ASP Course significantly increased their interest and intent to seek out more information about health care, participate in health care activities, and take more health care courses in high school. The qualitative evaluation found that the students and their parents were pleased with the MIM ASP Course's composition, presentation, and effectiveness. With a large majority of the parents stating that their child got out of the ASP Course what they had hoped for and that the ASP Course made it more likely that they would recommend a health career for their child. The students and instructional staff also identified the ASP Course elements that they felt were most and least effective.

5.2. Student Posters Encouraging Health Careers

Dr. and Mrs. Lindberg attended the "Yes, I Can be a Healthcare Professional!" Conference for five years straight at the Frederick Douglass Academy I in Harlem with the number of participants from the community ballooning to nearly 3,000 attendees. Meanwhile, the number of NYC participating schools grew to ten and, as one of their capstone projects, the students were charged with creating posters about health careers and/or diseases. After the first semester of the program, the culminating event for students to showcase their projects for the broader community was at the "Yes, I Can be a Healthcare Professional!" Conference. As the number of school-based programs increased, the number of middle and high student poster presentations greatly expanded. Students were expected to dress professionally as they stood beside their poster and presented the information. Conference participants were asked to grade each poster to choose a slate of prize winners in the middle and high school categories. Every year, Dr. Lindberg enjoyed engaging the students and examining their posters. That section of the conference was renamed the Dr. Donald A.B. Lindberg Exhibit Row to honor his wisdom and guidance in support of the MIM students.

After each conference, students from the program were invited to have lunch with Dr. Lindberg. He would participate in a lively exchange about a variety of topics to the amusement of the middle and high school students and their parents. Teachers from the various schools also attended the Saturday event with their students. Mrs. Lindberg actively participated as she shared her experience as a registered nurse. More importantly, both Dr. and Mrs. Lindberg strongly encouraged the students to pursue their dreams and that a health career and improving the health of their communities was very much needed--and possible for them to achieve.

5.3. Virtual Summer Science Camp

Nearly a decade before the reliance on virtual instruction to educate students during the COVID-19 pandemic of 2020, MIM became a leader in teaching urban students advanced scientific concepts and healthy living using NLM resources during the summer using synchronous e-learning. Created and implemented in 2012, the Virtual Summer Science Camp (VSC) utilized a hybrid method of instruction with "live" student audience and the virtual audience would engage with "live" speakers and activities. The Mentoring in Medicine Team was able to provide a novel meaningful project-based learning experience for students internationally beginning in middle school as demonstrated through formal evaluation of the summer of July 2012 in which the Cardiovascular

System was taught [5]. First, students explored a variety of careers in the health professions. Next, participants increased their information seeking behaviors about health. Students improved their health literacy and understanding of health disparity issues. They improved their test-taking and study skills. Finally, the participants understood advanced biological concepts and diseases affecting the cardiovascular system which was the subject matter of this initial VSC offering.

5.4. Community Health Ambassadors Program

In order to engage post-secondary school students on the journey to becoming a biomedical professional, the MIM Team launched the Community Health Ambassador Program (CHAMP) in 2007. College and post-baccalaureate students participated in a year-long academic enrichment, community service and mentoring experience. Students participated in outreach programs with MIM partners such as community-based organizations, churches, and food kitchens. In 2009, Dr. Holden was one of ten nationally recognized Robert Wood Johnson Community Health Leaders for creation and implementation of CHAMP.

During the 2009 Swine Flu pandemic, CHAMP students stood outside busy subway stations in Harlem and the South Bronx with health professional volunteers handing out bilingual NYC Department of Health information. In 2012, MIM partnered with the Icahn School of Medicine at Mount Sinai to help disseminate health messages in Harlem. Throughout a span of twelve months and 54 events, twenty-five Ambassadors were able to disseminate over 8,000 health messages to the East and Central Harlem communities.

CHAMP expanded to the high school level becoming an integral part of the in-school elective in 2018 allowing students to perform community service and improve health literacy in their school and local community. Examples of student projects included creating and displaying posters during lunch in the cafeteria describing influenza prevention and protection methods. Such activities are essential to empower the MIM students and to increase health literacy among their peers.

6. Replicating the MIM Programming

Dr. Lindberg received regular reports from the Outreach Team about the growth and progress of MIM. He was pleased with the reports and nicknamed Dr. Holden "the spark plug." Under his guidance, the MIM and NLM Outreach Teams created, implemented, evaluated and utilized the lessons learned to replicate the programs to a growing audience.

In 2012, at the urging of Mrs. Lindberg, Dr. Lindberg helped Mentoring in Medicine to establish the ASP in Washington, DC in Wards 7 and 8 which were especially adversely affected by health differences. This significant turning point was a huge leap for Mentoring in Medicine. The expansion and replication of services meant expanding the team and developing partnerships with schools, hospitals, and medical societies. Since Dr. Holden graduated from Howard University, she was able to build a network of health professionals, college student instructors and school contacts to implement the ASP in up to six middle and high schools. MIM also leveraged additional funding sources to sustain and grow the number of schools participating.

6.1. Science Day at the National Institutes of Health

Dr. Lindberg also helped to replicate the Harlem Fair focusing instead on science on the campus of the National Institutes of Health (NIH). In 2014, a large event to expose students to biomedical science was launched. The Science Day for Students at NIH has been co-sponsored by the National Library of Medicine and the National Institute on Minority Health and Health Disparities and held for seven years with over 3,000 DC area minority students and up to 20 NIH Institutes participating [6-8]. In 2021, due to the COVD 19 pandemic, the event expanded virtually allowing the MIM NYC schools to also participate.

7. Lessons Learned

Using the qualitative research methodology of focus groups allowed MIM to develop insight and direction before designing and implementing the school-based programs. MIM programming incorporates important elements that can serve as best practices for other health career-oriented educational interventions with underrepresented minority students in urban settings: (a) Know and understand all aspects your target population, including their attitudes, beliefs, and concerns; (b) Address disincentives, such as family financial limitations, peer pressures, and the lack of positive role models; (c) Develop programming that is comprehensive, long-term, and participatory; (d) Develop programming that is age and grade appropriate, encompassing and reinforcing the journey that students make from middle school to high school, through community and four year college, and enrollment by some in graduate professional school; (e) Venture outside the traditional classroom to offer after school courses, and experiment with information and computer technologies that support interactive virtual learning; and (f) Provide individual and group mentoring whenever possible, including exercises that build self-confidence, promote social and emotional skills strengthening, and enhance study and test-taking skills. In consistent independent evaluations, it was found that the lower performing student in school excelled in the Mentoring in Medicine program. This was good news to try to capture those students with great potential!

Building upon the initial focus groups, MIM designed school-based courses that capture student interest, foster motivation/engagement, impart knowledge/skills, and change attitudes thus building student confidence in their capability to succeed while being relevant to their economic, social, community, and cultural backgrounds. In addition to teaching the anatomy, physiology, and pathology, the MIM school-based course has several unique features which include growth mindset instruction through an equity lens addressing health care disparity issues and social determinants of health affecting the students' communities. The courses infuse youth culture (e.g., use of animated and video materials, rap and spoken word in projects) and current events into the curriculum increasing the interest and participation of the students. It helps increase the curiosity for learning by understanding the students' conceptual framework. The students are motivated by culturally relevant role models who visited the classroom and discuss their journey to a healthcare career and their strategies for success. The hands-on activities appeal to the multimodal learner. (See Photo 3.) Parents are involved in the program (e.g., pre and post surveys, newsletters), thus creating partnerships with the students' key career influencers. The MIM team provides a low risk, safe academic

environment which encourages students to participate in classroom activities as individuals and as part of small groups (e.g., classroom games – Jeopardy).

Photo 3. At a MIM workshop, students learn about how to dissect pig hearts, under the guidance of medical professionals.

8. Conclusion

The growth of Mentoring in Medicine is attributable in no small measure to the support and direction of Dr. Donald Lindberg and his Outreach Team; especially the late Dr. Donald King who united the organizations and enabled the MIM Team to make a tremendous impact on the lives of so many students. MIM programs grew from NYC then expanded to Washington, DC and nationally. MIM became an innovative educator of students at all grade levels, thus, building a continuity of programming with live, interactive, and virtual capabilities. MIM has impacted nearly 58,000 students, parents, and educators in the U.S. MIM has helped 503 students who were discouraged to build a competitive application and matriculate in health professional school. MIM has 88 press features highlighting our work in the community. MIM has become a national organization known for cultivating and grooming students beginning in elementary school, who are underrepresented in the fields of health care and health sciences.

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Are We Making a Difference?
Outreach Evaluation in Practice

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Abstract. Donald A.B. Lindberg, M.D., brought with him when he joined NLM an inquisitive mind, tech savvy, and new ideas. He was an early advocate of both outreach and evaluation innovation at NLM. Dr. Lindberg initiated and supported multiple pilot test and implementation projects to strengthen NLM's health information outreach to healthcare providers, research scientists, health science and hospital librarians, and the general public, including minority and underserved populations. He helped steer NLM's transition to the Internet, and NLM's development of a robust framework for evaluating Internet and Web-based health information dissemination and outreach to its many audiences. Dr. Lindberg's leadership led to numerous landmark accomplishments, including the capacity-building "Measuring the Difference" outreach evaluation Guide, and a multi-dimensional approach to Internet and website evaluation that placed NLM at the forefront of federal agencies using these new and emerging technologies to support their missions.

Keywords. U.S. National Library of Medicine, Donald A.B. Lindberg M.D., outreach, evaluation, health information dissemination, Internet performance, websites, usage data, user surveys, customer satisfaction, web data analytics.

1. Introduction

Are we making a difference? That is a question we commonly ask ourselves in middle-age or, retrospectively, in our later years when the answer has become relatively clear. But it applies as well to organizations - and Donald A.B. Lindberg, M.D., Director of the National Library of Medicine (NLM) challenged the institution with that fundamental question not long after his arrival at NLM in 1984. Following the successful completion of the Library's first formal long range planning effort that benchmarked existing programs against new opportunities, Dr. Lindberg wanted to know if we are asking how effective are NLM's products and services [1]? Are we reaching the people who should be our users? Are we meeting their needs? What are the benefits and outcomes? How might our products and services be changed and improved in response*?* Dr. Lindberg was thinking specifically of NLM's premier offering, the online MEDLINE (later to be remade as PubMed) database of biomedical literature citations and abstracts that is used all over the world and, at that time mostly by NLM-trained medical librarians who served as intermediary searchers on behalf of their end-user patrons.

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1.1. The Critical Incident Technique Study of MEDLINE Users

Dr. Lindberg suggested using the Critical Incident Technique (CIT) evaluation methodology to identify answers to some of these questions [2]. First used in World War II to identify characteristics and behaviors of successful bomber pilots, the CIT became widely used after the War by psychologists in personnel selection and in a variety of other settings; several in the medical community but none in the library community. Dr. Lindberg tasked Elliot R. Siegel Ph.D., then Assistant Director for Planning and Evaluation, to adapt the methodology for NLM's use.

Siegel's CIT study was designed to gather detailed reports of MEDLINE searches that were especially helpful (or not helpful) in carrying out the full range of professional activities of more than 550 physicians, scientists, and other professionals working in a variety of clinical care and other settings. Of these, two-thirds were direct users of MEDLINE who were purposefully recruited for the study; the remaining were academic health sciences and hospital librarians who recounted searches performed by them for others. More than eleven hundred *CIT* reports were systematically content analyzed from three different perspectives: why the information was sought, the effect of having (or not having) the needed information on professional decisions and actions, and the outcome of the search.

In clinical settings, the study documented that MEDLINE searches were being carried out by and for physicians to meet a wide diversity of clinical information needs. Rapid access to the biomedical literature via MEDLINE, for example, was critical to sound patient care and favorably influenced patient outcomes [3]. All interviews were conducted by telephone and typically lasted 30 minutes. The protocol benefitted greatly from Dr. Lindberg's insistence that the first 50 calls be pilot tested and conducted personally by Siegel, rather than by the interview-skilled but non-medically experienced contractor's staff, to sharpen and refine the interview questions. A valuable hands-on lesson that benefitted Siegel's evaluation work in the years ahead.

1.2. Evaluation at NLM Pre-Lindberg – A Promising Beginning

In the early 1980s, the traditional 'wood' book catalog was replaced, and a microform system was installed in its place in libraries without the benefit of evaluation. It proved to be unpopular with both patrons and staff. Then NLM Director, Martin M. Cummings M.D., tasked Siegel with performing a comparative evaluation of two home-grown prototype online catalog systems in the NLM Reading Room, much to the consternation of some staff who were uncomfortable with the perceived intrusion by the front office and the prospect of discomforting patrons. The patrons never complained and seemed intrigued by the new computer monitors and the opportunity to help test a leading-edge technology that could make searching the collection far easier and more effective. A clear favorite amongst the two electronic search systems was identified. Its demonstrated reliability and superior functionalities proved superior to the other system, and of course to the static card catalog it permanently replaced [4].

Dr. Cummings was the inspiration for another notable early evaluation when he returned from an annual Congressional Appropriations hearing greatly frustrated that once again, he was unable to answer a simple question with any precision - Who uses MEDLINE? Cummings approached Siegel who created what turned out to be NLM's first MEDLINE user study, an early precursor of the CIT study.

It was implemented in a far less rigorous manner; self-selected anonymous MEDLINE users responded to a brief two question online survey that identified their professional (or public) role and the intended purpose of their search. Staff resistance to the possibility of burdening searchers was overcome with the realization they would now have greater insight into the actual identity and needs of their users, especially those for whom the librarian-conducted searches were being performed. The study findings provided Dr. Cummings with a credible answer for the next hearing, much to his delight.

Investigators at NLM and at other institutions later undertook descriptive MEDLINE user studies of their own [5]. Many more would follow the pathfinding CIT study, benefitting from new analytic tools, technologies, and policies that evolved, and are recounted later in this chapter. An early example was a nationwide field evaluation of MEDLINE products on CD-ROM that was organized by NLM under Dr. Lindberg's careful watch. He viewed the CD-ROM as a transitional technology soon to be replaced by Internet access. Nevertheless, the commercial products existed, and the Library needed to assure itself and the community of users that their technical performance and user acceptance met acceptable standards [6]

1.3. Dr. Lindberg's Influence – A Mandate and A Way Forward

It was Don Lindberg and the CIT study he initiated and personally guided that would lead to the establishment of a robust tradition of evaluation research at NLM. Dr. Lindberg made evaluation an accepted and a necessary requirement to study our users and ask the hard questions of them and of ourselves as program managers - *Are we making a difference*? He expanded Siegel's role to include responsibility for coordinating and guiding NLM's outreach activities and evaluation research throughout NLM and, indeed, introducing new evaluation tools and methodologies to the entire National Institutes of Health (NIH) community as detailed in this chapter. Siegel was joined in 1995 by Frederick B. Wood, MBA, DBA who collaborated closely as lead evaluator in the newly established Office of Health Information Programs Development (OHIPD), within the Office of the NLM Director. Together, Siegel and Wood developed and coordinated new outreach initiatives that sought to include a strong evaluation component.

2. Evaluating Outreach

Dr. Lindberg brought with him many new ideas that motivated staff to pursue exciting opportunities for change. Among these was the need for a comprehensive long-range plan, the first of its kind for NLM, that was completed in 1987 [1]. A variety of important program possibilities were identified, many of which were ultimately implemented and are discussed elsewhere in this book. One novel possibility subsequently recognized by Congress encouraged NLM *"…to develop an outreach program aimed at… [the] transfer of the latest scientific findings to all health professionals …"* [7]. The mission of NLM was also explicitly amended to add the function to *"Publicize the availability of [its] products and services…"* [8]

This outreach function was pursued in 1989 as a pivotal update to the plan, which was known as the *DeBakey Report*, in honor of famed heart surgeon Dr. Michael DeBakey who chaired the outreach planning panel [9]. Its focus was on connecting

unaffiliated health professionals in rural and underserved communities to medical libraries. When the Internet subsequently made possible access to NLM's information resources without a telecommunications cost to the Library in the mid-1990's, NLM's outreach commitment was significantly expanded to include patients, families, and the general public.

Dr. Lindberg also strongly encouraged a focus on enhancing the capacity of underserved and minority populations to access health information, consistent with the societal goal of reducing health disparities amongst Black, Hispanic, and Native American populations. Selected outreach initiatives developed by OHIPD are discussed in the following sections of this chapter, along with the evaluation methodologies used to assess their outcomes and the effectiveness of the strategies employed in their development and implementation. Additional outreach initiatives carried out by NLM's health sciences and public library partners are discussed in the accompanying chapter, NLM's Library Network: A Force for Outreach [10]

2.1. Outreach Evaluation: the First Five Years

With the availability of newly appropriated outreach funding in the five years between 1989 and 1994, NLM undertook and supported close to 300 outreach projects involving more than 500 institutions across the country. The key to these efforts was the close collaboration of the National Network of Libraries of Medicine (NN/LM).

In 1995, the OHIPD coordinated a comprehensive evaluation of these outreach activities [11]. The review found very substantial progress in engaging and training individual health professionals to use MEDLINE via the Library's end-user-friendly interface, GRATEFUL MED. The number of user codes issued increased from approximately 30,000 to almost 100,000 during that time period. There were four million searches of NLM databases in 1989 vs. seven million in 1994. GRATEFUL MED users in 1989 accounted for less than one-third of the searches, in 1994 they conducted more than two-thirds of the searches.

These metrics were certainly very useful indices of impact, but with few exceptions these outreach projects did not get at the fundamental underlying question posed by Lindberg - *Are We Making a Difference?* - nor did they address the need for intensified outreach to minority populations, and the institutions serving their health information needs at the community level.

A significant part of the identified outreach evaluation challenge was that the library staff undertaking the outreach had little or no formal training in evaluation. They had limited ability to plan an evaluation project, and to articulate answerable questions that surpassed 'counting heads.' Nor was there available an appropriate training resource that could fit their current skill set and bring them to the next level.

2.2. Measuring the Difference: Guide to Planning and Evaluation Health Information Outreach

We published an Outreach Evaluation Guide in 2000 as a capacity-building effort. It was a partnership of the NLM and the Pacific Northwest Regional Medical Library (PNRML) at the University of Washington. The lead author was Catherine Burroughs, MLS, at the PNRML, and the project officer was Dr. Wood. The project included an advisory group of community outreach and evaluation experts, several of whom prepared background

papers. For an extensive list of advisors and staff contributing to this landmark effort, see the guidebook acknowledgements [12].

The underlying themes of the Guide were: planning and evaluating an outreach initiative is one and the same process; and asking the right questions at the beginning was essential to obtain useful results. Moreover, the Guide was practical in purpose, theory-based, and offered a range of methodological possibilities and strategies that could be adapted to the simplest or most complex of outreach projects. The NN/LM also established an Outreach Evaluation Resource Center (OERC) at the PNRML that could serve in a consulting capacity to member libraries using the Guide and needing hands-on outreach evaluation and related assistance.

As a follow-on to the original manual, the OERC issued a set of three shorter guidebooks (in booklet form) for key stages of outreach evaluation, initially released in 2006 and updated in 2013 [13]: The principal authors of the series were Cynthia Olney, Ph.D. and Susan Barnes, MLS, MS, both at the OERC. The booklets were intended to help address the need of NNLM outreach staff for stronger evaluation skills, with specific emphasis on the Logic Model methods of evaluation that provides a straightforward relationship between project goals, process, and outcome measures. For further discussion of Logic Model applications, see the companion chapters on the NLM's Library Network: A Face of Outreach [10] and HIV/AIDS Community Information Outreach Program [14].

For further background on evaluation of community-based outreach projects, see the proceedings of the 2004 symposium on this topic co-sponsored by the NLM and NNLM, and especially the overview article, and an article by Dr. Charles Freidman on right sizing outreach evaluation and the use of smaller and incremental evaluations where appropriate [15-17].

2.3. Transitioning to the Internet

The overall framework for outreach evaluation from the mid-to late 1990s onward increasingly reflected the emerging Internet platform for biomedical and health information dissemination. Dr. Lindberg was an early leader in the arena of health on the Internet. He developed a long-term interest in medical informatics and served as the first director of the Federal Government's Office of High-Performance Computing and Communications (HPCC). For several years, Dr. Lindberg wore two hats, NLM Director, and HPCC Director.

Dr. Lindberg was well positioned to discern and foresee the coming Internet revolution and its profound implications for NLM. The Internet would transform how NLM conducted its core information dissemination activities and its outreach around those activities. And likewise, NLM's evaluation activities needed to evolve and adapt to the Internet.

Under Dr. Lindberg's leadership, NLM needed to address such topics as:
- Access of minority, underserved, and minority communities to biomedical and health information via the Internet;
- Technical performance of the Internet to assure that users are receiving NLM's data and information in a timely, efficient, and accessible fashion;
- Customer satisfaction with the NLM's electronic information platforms, and increasingly NLM's websites;

- A comprehensive approach to monitoring and assessing NLM's website and other electronic information resources.

Thus, the need for new or revised evaluation approaches that would work in the increasingly electronic customer service and outreach environment.

3. Outreach Implementations and their Evaluation – Examples from the Field

This section highlights several key community-based outreach initiatives that NLM implemented to address Dr. Lindberg's outreach vision, and the means used to assess the effectiveness of their processes and the success of their outcomes.

3.1. Tribal Connections

The five-year review of NLM outreach concluded that NLM outreach to Native Americans was too limited. In response, NLM reached out to Sherrilynne Fuller, Ph.D., director of PNRML and a committed advocate for Native American outreach. Tribal Connections became a long-running partnership between NLM and the PNRML and was one of NLM's first major outreach projects with a Native American focus.

Tribal Connections was intended to use a community-based outreach approach to improve the Information Technology (IT) infrastructure and Internet access at select Indian tribes and Native villages and provide training in online access to NLM health information. Tribal Connections was designed to run in parallel with the aforementioned project to develop an outreach evaluation Guide. The intent was that Tribal Connections could benefit from and contribute to the evaluation methods project.

Tribal Connections Phase 1 reached 16 Indian tribes and Native villages in the Pacific Northwest (Washington, Alaska, Montana, Idaho, and Oregon). Each site was intended to have community outreach with one or more site visits, collaborative needs assessment, customized technical support, purchase of necessary IT equipment and services, Internet connectivity upgrades or partnerships as needed, and associated technical and other training. At the time of this project, Internet connectivity at the participating sites ranged from 56 Kbps dial-up, 128 Kbps ISDN, to full T-1. Each site plan was optimized for the baseline Internet connectivity and realistic upgrade options. For detailed discussion of Phase 1, see [18-19].

Later phases of Tribal Connections included the addition of four sites in the Southwest, more intensive training and outreach at selected sites, and a collaboration with medical libraries serving American Indians in the Four Corners Area (parts of Arizona, New Mexico, Utah, and Colorado) [20-21]. The latter project was known as Tribal Connections Four Corners (TC4C).

From an evaluation perspective, the projects early on relied heavily on performing needs assessments with local tribal leaders and key staff, whose engagement and understanding of the technical infrastructure improvements proved to be the single most important factor in determining a successful outcome. Internet connectivity was successfully established at nearly all sites, and training in its use was assessed which identified areas needing improvement. Implementations in the later project phases added measures to better understand the impact on information seeking behavior and actual health-related decision-making.

Dr. Lindberg requested periodic Tribal Connections briefings, several of which occurred at meetings of the NLM Board of Regents. Although not foreseen at the time, Tribal Connections helped lay the groundwork for the subsequent Native Listening Circles and Tribal Consultations that led to NLM's Native Voices exhibition which is discussed in a companion chapter [22].

3.2. Health Information Hispanic Outreach

The 1995 NLM outreach review also concluded that NLM outreach to Hispanics was limited and needed a boost. A key element of the NLM initial response was the "Health Information Hispanic Outreach" project in the South Texas Lower Rio Grande Valley. The NLM 'HIHO' project was built in part on earlier NLM circuit rider outreach pioneered by the iconic Mary Jo Dwyer who made the rounds from San Antonio to visit small, rural libraires and hospitals in South Texas. She helped facilitate access to NLM health information, at first in paper and CD formats, and later via the nascent Internet. Under the direction of Virginia Bowden Ph.D., at the University of Texas Health Sciences Center at San Antonio (UTHSCSA), HIHO included a needs assessment, focus groups, and surveys. It identified additional outreach needs and two specific initiatives for further study: a high school peer tutoring project, and a *Colonia Promotoras* project [23].

The Peer Tutoring project emphasized the training of high school students at health-focused high schools to serve as "peer tutors" to other students. The peer tutors helped students understand NLM's online health information resources, MedlinePlus, and MedlinePlus en espanol, and how to use the Internet and World Wide Web to access such information. Peer tutors also were coached on how to provide peer leadership and outreach to local communities, at events such as health fairs, to further enhance health information access. The school librarians and UTHSCSA librarians teamed with high school teachers and staff to provide guidance and training to the peer tutors. Most of the students in these schools were of Hispanic origin, and many would be among the first in their families to graduate from high school and go on to some form of higher education. The Peer Tutor project had an evaluation specialist from the outset, Dr. Olney, who assured that the "Measuring the Difference" manual was properly applied. Each phase of the peer tutor project was evaluated on a variety of process and outcomes measures [23-25]. For many peer tutors, the experience was life changing and helped motivate them on to community or four-year colleges. They continued to use MedlinePlus beyond their high school graduation, and to advocate for family and friend's use of MedlinePlus. Dr. Lindberg very much enjoyed meeting with the peer tutors and school librarians when they visited NLM and presented at the NLM Board of Regents. Reaching out to and enabling the next generation of student and library leaders was always a priority for Dr. Lindberg.

The *Colonia Promotoras* project deployed Hispanic community outreach workers and health advocates, many of whom were bilingual [26-27]. The *Promotoras* served as intermediaries between NLM health information accessible at local computer labs, and low-income community residents of the *Colonias* which are unincorporated towns near the Texas border with Mexico. The *Promotoras* submitted written reports of the health topics they helped residents explore on MedlinePlus and the ways in which the residents used the information. These reports along with verbal interviews constituted a database of "stories" that were like those collected in the original NLM Critical Incident Technique study. Dr. Olney was the project evaluator.

4. Internet/Web Evaluation - A Multidimensional Approach

Under Dr. Lindberg's leadership of NLM, evaluation was a watchword for understanding and assessing information technologies and services. The advent of the Internet and World Wide Web (WWW) are cases in point.

During the decade from 1996 to 2006, with Dr. Lindberg as an active helmsman, NLM went from the very beginnings of a framework for evaluating the Internet and WWW for biomedical information dissemination, to a robust and comprehensive framework.

This section recounts the development of an integrated, multidimensional framework for NLM website evaluation: The major dimensions of this framework include:

- Internet technical performance;
- Website usage data;
- Website customer satisfaction data;
- External benchmarking survey data; and
- External benchmarking usage data [28-29].

4.1. Internet Technical Performance

The first evaluation component that NLM focused on was the technical performance of the Internet. New NLM policy encouraged use of the Internet to access the Library's information resources from international locations. Soon enough, Dr. Lindberg was receiving complaints from colleagues in other countries, specifically the United Kingdom and Western Europe, about the slowness of the Internet traffic coming from the United States. Dr. Lindberg asked Dr. Siegel to investigate these concerns. Dr. Lindberg assembled a team including himself, Dr. Wood, and Victor Cid from NLM's Office of Computer and Communication Systems (OCCS).

Dr. Wood was an electrical engineer with experience in technology studies and extensive prior work at the Congressional Office of Technology Assessment in the information technology arena. Mr. Cid, a computer scientist, had just completed a seven-year project with the BITNIS, a pre-Internet system for responding to user requests for information from NLM's MEDLINE. BITNIS users originally were clustered in South America and later extended to other geographic areas. BITNIS ran on BITNET, which was a technical network using telecommunications and packet switching among then-dominant mainframe computers [30]. Mr. Cid was familiar with the Internet network architecture and operations at this very early stage. In 1995, BITNET was being phased out in favor of the then nascent Internet.

The OHIPD-OCCS team developed one of the first frameworks for monitoring and measuring Internet quality of service. At the time, there was no widespread commercial Internet performance monitoring system, but there were a few start up companies and engineering experiments.

NLM met with Internet engineering researchers and experts, and developed a system to monitor the bandwidth, speed, and routing of packets of information moving over the Internet. NLM's system tracked packets between NLM's computer center and host computers at partnering institutions in the U.S. and abroad. These were from the NNLM, and overseas from the International MEDLARS Centers which were distribution points for access to MEDLINE data stored in the participating home country's library or

information center. The MEDLARS Centers proved to be important for several years prior to and during the transition to the Internet.

The technical testing metrics and tools used by NLM included:

- Transmission capacity, the bandwidth or size of the Internet "pipe" (aka, Bulk Transfer Capacity, megabits per second, using for example the TReno test);
- Latency or delay (aka, Round Trip Time for packets of data to go from the sending to receiving location and back using the Ping test);
- Network routing (aka., the number and sequencing of links or hops that the data take from origin to destination (using for example the Traceroute test). Note that physically a hop is a segment of telecommunications network between pairs of switching centers or routers through which packets of information transit to "hop" along an interconnected Internet pathway from sending to receiving locations.

With a test network at home and abroad, and using the metrics and test tools mentioned, NLM was able to answer Dr. Lindberg's questions about Internet connectivity and performance.

The delays in Internet traffic between the U.S. and the UK and Western Europe were occurring not in the U.S. when Americans were sleeping, but from the UK/European side due to inadequate local infrastructure and the increase in their own Internet traffic associated with the beginning of their business day. This pattern held for several other countries as well.

Further testing showed that the speed of the Internet traffic depended on the bandwidth of the pipe, the time of business day at the sending and receiving locations, and the types of content being transmitted. This Internet performance evaluation approach was of great interest in the U.S., to the Federal Government, private companies, and academic institutions alike, and to international groups such as the G-7 [31].

Eventually, NLM migrated to commercial Internet performance companies, such as Keynote, that assembled their own monitoring networks and provide Internet performance data on a wide-scale basis. The data could be used for benchmarking, Internet capacity planning, and trouble shooting.

In 1998, the NLM team published a landmark paper on this topic in the Journal of the American Medical Informatics Association [32]. Also, the NLM team taught a continuing education class on this topic at the annual AMIA meeting. And Internet performance was included in other NLM and NNLM projects, see e.g..[33].

Internet performance and quality of service continues to be an integral part of Internet network management and engineering in the U.S. and globally, by the IT departments and/or commercial providers, for most organizations of all types and sectors, including the NLM OCCS.

4.2. Website Usage Data

In the late 1990s, NLM transitioned to website-based platforms for information dissemination and database access, using the rapidly expanding Internet. Dr. Lindberg was vitally interested in understanding the usage of NLM websites, as they became the primary information platforms for NLM.

Dr. Lindberg's driving interest helped prompt the use of successive generations of web log software by most NLM websites. In order to meet Dr. Lindberg's desire for usage data across NLM websites, the OHIPD coordinated a trans-NLM project to collect

and make available key usage data for the larger NLM websites. The primary metrics selected were:

- Number of website visitors;
- Number of pages downloaded; and
- Number of database searches (where applicable).

There was considerable debate about how many and which metrics to include, and how often to collect data. The consensus was to include a small number of required core metrics but allow individual websites to use additional metrics if needed. Most web log software then and now provide additional options, such as first time versus repeat visitors, time per visit, visits per use, and pages most frequently visited. The consensus was to collect data monthly but report on a quarterly basis. The NLM operating divisions assigned staff to manage the data collection and reporting. The data were accessible to all interested NLM staff via the NLM Intranet. This usage data collection and reporting framework worked well for many years.

At the same time, web log software and metrics continue to evolve, and NLM has periodically upgraded and transitioned to newer software packages and systems. NLM is well on its way to implement the type of website data management that Dr. Lindberg dreamed of years earlier but was not yet fully possible in his working lifetime. He would have been very pleased about the progress being made.

4.3. Web User Satisfaction Data

In the pre-Internet era, Dr. Lindberg was always interested in user opinions of and satisfaction with NLM's health information resources and databases. Pre-Internet, NLM was able to conduct or sponsor surveys of library patrons, since most access to NLM information physically occurred in a library setting. In a transitional electronic environment, such as Internet Grateful Med, users were required to sign up and pay a connection fee for service. Thus, their names and contact information were known, and they could be contacted with in person, mail, or email customer satisfaction surveys.

NLM's transition to the free Internet, with no sign up requested or required, fundamentally changed the customer feedback process. NLM no longer had user contact information, and thus could not use standard survey methodology. New, online survey methods were needed and developed.

NLM quickly found that customer response rates to online queries were much lower than in person surveys or surveys mailed to known customers. It was common to obtain 50 percent or even 75 percent response rate from paper surveys in library settings. In contrast, a typical response rage in online surveys was and still is typically five-ten percent at best, and frequently three to five percent. This raises serious questions about non-response bias.

NLM studied the options for online surveys and ended up heavily using the American Customer Satisfaction Index (ACSI) online survey services, for many years from about 2000 through 2018 [34].

4.3.1. Using the American Customer Satisfaction Index (ACSI) to Conduct Online Website User Surveys

- The ASCI had several advantages:
  - o it was based on a rigorous survey methodology developed by University of Michigan survey and communications specialists,

    o   it used a standardized methodology with core questions designed for website users;

    o   it was offered at an affordable price via a U.S. Government-wide contract with ForeSee Results Inc. and

    o   it had pre-approval from the Office of Management and Budget, which needs to approve all major U.S. Government sponsored surveys.

NLM found the ASCI via ForeSee Results to be more cost-effective than contracting for individual surveys. Also, the ACSI was good public relations for NLM, since some NLM websites, and especially MedlinePlus English and MedlinePlus en Espanol, were always among the best performers.

- These results were shared with NLM management and, occasionally, the NLM Board of Regents.
- NLM and some other NIH institutes and offices partnered to sponsor at the time the largest agency wide ACSI survey program in the Federal Government. About 60 NIH websites participated in the two-year project, with most funding provided by the NIH Evaluation Set-Aside Program.
- The NIH team, co-led by NLM, conducted an evaluation that confirmed the value of online customer surveys.
- However, after the special project funding ran out, more than half of the NIH participating websites could not be renewed due to insufficient funds.

NLM continued to use the ACSI for about a half dozen websites for many years, but eventually decided to phase out the ACSI and try other options. At the time of the lead author's retirement, NLM had shifted to using Qualtrics as the primary survey provider, which provided more flexibility and customization compared to the ACSI, but did not provide the benchmarking possible with the ACSI. NLM also used newer versions of the Survey Monkey online survey.

The bottom line seems to be that Dr. Lindberg's desire to have website user or customer feedback is still being fulfilled, albeit with changing survey platforms over time. Customer feedback is an important part of the NLM's comprehensive website evaluation framework developed during Dr. Lindberg's tenure [28-29].

4.4. External Benchmarking

Dr. Lindberg also was interested in how NLM website performance compared with other websites, in other Federal agencies and in the private sector. In response, OHIPD pursued two avenues to obtain external data on online health consumer and physician use of and satisfaction with online health websites; and to obtain comparative data on health website usage [35].

4.4.1. Benchmarking NLM website data with external comparative data.

- Comparative customer survey data: NLM purchased access to the results of syndicated nationwide surveys of online health information consumers and health providers.
  - o   These surveys, known as Cybercitizen Health (consumers) and Taking the Pulse (physicians), were conducted annually with large stratified and randomized samples.

o   The surveys provided insights into how consumers and physicians behave online, what types of information they seek or provided, and their uses of this information.
o   Typically included were questions on the most frequently used information sources accessed by consumers and physicians. These data provided some sense of the relative frequency of use of comparative and competitive health information websites in NLM's market space.
o   The Cybercitizen Health and Taking the Pulse surveys were first conducted by Fulcrum Analytics, which was later bought by Manhattan Research, which was later bought by Decision Resources, Inc.
o   Comparative web usage data: NLM purchased access to website usage benchmarking services that had their own large panels of online users that agreed to monitoring of their web usage. This allowed the collection of third-party usage data for different types and categories of users and websites.
o   NLM was particularly interested in comparative usage data in the following categories:
   ➢   Federal agency websites.
   ➢   Federal health agency websites.
   ➢   Federal science agency websites
   ➢   Commercial and non-profit health information websites.
   ➢   Subsets of disease and condition websites.
o   The first usage benchmarking service NLM used was known as PC Data, which was bought later by comScore Networks.

These syndicated survey and benchmark services are relatively cost effective since costs are spread over multiple websites and clients. However, after many years, NLM eventually decided not to continue these services, in part because, while the top line results were informative, they were relatively unchanged year to year. Thus, the perceived value added declined. While the services were phased out in 2017, they did provide a useful measure of comparative market intelligence not otherwise available during the formative years and full implementation of NLM's presence on the Internet and WWW.

5. Conclusions

Among Dr. Lindberg's many legacies, he put both evaluation and outreach on the NLM map. He had the foresight and perspective to understand early in his service as NLM director that evaluation needed to be an integral part of NLM's health information outreach and dissemination portfolios.

Evaluation is a key to understanding and assessing how programs and projects are working, whether they are meeting their goals and objectives, and how they may be improved or modified or phased out going forward. And yes, assessment helps answer Dr. Lindberg's initial question, "Are we making a difference?"

Within the outreach domain, two defining evaluation contributions developed during Dr. Lindberg's tenure were: 1) a health information outreach program evaluation Guide and updated field manuals, along with a dedicated NNLM evaluation office that could support local outreach project managers where they are; and 2) a multidimensional

approach to Internet and website evaluation that placed NLM in a leadership position at the forefront of federal agencies learning to use and benefit from these technologies.

The outreach evaluation manuals (aka field guides or booklets) are still in circulation and available on the NNLM website, and NLM is still supporting the current manifestation of the original Outreach Evaluation Research Center. OERC became the NNLM Evaluation Office (NEO and is now known as the NNLM National Evaluation Center (NEC) and has relocated from the University of Washington Health Sciences Library to the Northwestern University Feinberg School of Medicine, Galter Health Sciences Library & Learning Center.

The foundational multidimensional web evaluation framework is still largely operational in some form at NLM. It has managed to transition through multiple advances in the underlying information technology and evolution of web evaluation methods, metrics, and software.

Other components and elements of success of Dr. Lindberg's evaluation legacy include: senior level leadership; adequate funding; staff support and training; and documented evaluation results (including peer-reviewed published papers where appropriate). With these ingredients, outreach evaluation at NLM can continue Dr. Lindberg's evaluation legacy.

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NLM's Library Network: A Force for Outreach

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Abstract. This chapter considers the transformation of U.S. National Library of Medicine's (NLM) national network of libraries into an effective force for spreading awareness of NLM's resources, services, and tools and increasing their use. Several examples of network programs and projects are recounted to illustrate the influence of NLM's longest serving Director, Donald A.B. Lindberg M.D. on the development and evolution of NLM''s library network.

Keywords. Outreach, National Network of Libraries of Medicine (NN/LM0, Regional Medical Library, U.S. National Library of Medicine, Donald A.B. Lindberg M.D.

1. Introduction

The Medical Library Assistance Act of 1965 did several things to improve medical library facilities, resources, automation of library services, and training of librarians. The Act also led to the creation of the Regional Medical Library (RML) network, coordinated by the U.S. National Library of Medicine (NLM), which was designed to facilitate resource sharing among hospital libraries, academic libraries, and NLM. This network was successful in improving access to medical information for health professionals connected to its nodes. By the 1980s, it became increasingly clear many health professionals did not have access to a medical library nor access to the latest medical information. The development in personal computer technology and public communication networks began to make it possible for individuals to get access to information without having physical access to a library.

Appreciation of these developments led Congress, in 1987 and again in 1988, to encourage NLM to develop an outreach program to reach health professionals in all areas, including rural and other under-served areas, and to amend NLM's mandate to include "…publicize the availability of [its] products and services..." [1]. In response, the NLM Board of Regents commissioned an outreach planning panel in 1988, chaired by Dr. Michael E. DeBakey. The panel delivered a report to the Board entitled *Improving Health Professionals' Access to Information* [2]. The Board approved the report in 1989.

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Among the key recommendations of this influential and far-reaching report was the refashioning and retooling of the RML network into a national "field force" for NLM. Other recommendations addressed new and expanded grant programs, training programs in biomedical information management, and development of new products and services. Results of these developments are covered in other chapters in this book. This chapter focuses on the National Network of Libraries of Medicine (NN/LM), renamed as recommended in the report to emphasize its national structure and direction [See Figure 1].
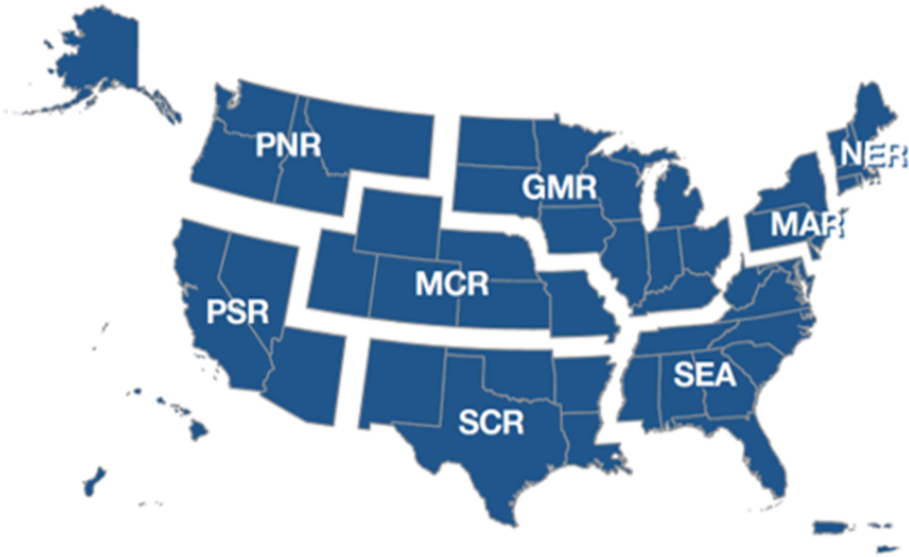
Figure 1. NN/LM Map – showing the Regional Configuration from 1991 to April 2021

None of this would have happened without the vision and efforts of Donald A.B. Lindberg, M.D., Director, U.S. NLM. He arrived at the Library in 1984 with great admiration for the Network and a desire to expand its scope and increase its effect.

Wallingford et. al. provide a detailed review of the first five years of NLM's outreach programs (1990-95), including programs performed by the NN/LM [3]. This chapter focuses on key NN/LM outreach projects and initiatives following this initial period. The areas highlighted are necessarily selective of the whole and represent Dr. Lindberg's particular interests and influence. Speaker's history of the NN/LM from 1985-2015 gives a broader overview of the program during Dr. Lindberg's tenure as NLM Director [4].

2. Initiatives

2.1. Information Access

With his FY2013 statement serving as an exemplar, in each annual Opening Statement to the House Subcommittee on U.S. Labor-HHS-Education Appropriations, Dr.

Lindberg advocated strongly for NN/LM's role as NLM's outreach program: "To be of greatest use to the widest audience, NLM's information services must be known and readily accessible" [5]. NN/LM was indeed a major force in raising awareness and increasing effective use of NLM services, databases, and tools. For example, through NN/LM resource sharing agreements and training by dedicated NN/LM staff, librarians established coordinated interlibrary loan and document delivery services using NLM's resource sharing products and systems. These included DOCLINE for interlibrary lending and borrowing, LinkOut to lead PubMed users to their libraries' collections, and Loansome Doc linked to Grateful Med, and later PubMed, to provide users the ability to request journal articles at the click of a button. Through delivery of documents--digital images or copies, and interlibrary lending of books and audiovisuals - NN/LM's resource sharing program offers health professionals access to resources not limited to a single local library. Time is nearly always of the essence in document delivery and interlibrary loan of health information. A smoothly functioning resource sharing program minimizes the time lapse between requesting an article, book, or audiovisual and its receipt.

2.1.1. Loansome Doc

Dr. Lindberg wanted anyone searching for journal article citations and abstracts through Grateful Med and later PubMed to easily obtain the retrieved articles' full-text information, including those unaffiliated with a health sciences library. Thus, the advent of Loansome Doc. This feature encouraged users to register with an NN/LM library to obtain physical copies of journal articles through clicking on article citations identified in their literature searches. The user established a profile with a library and agreed to its service terms and prices. Library details were added to the user's Loansome Doc profile to create the link between the user and the library.

Loansome Doc was tested by the Pacific Southwest RML of the NN/LM in 1990-91. NN/LM regional offices conducted extensive training for health sciences librarians to familiarize them with the system and to understand what policies were needed to deliver journal content. NN/LM also exhibited the service and performed associated training sessions at health professional conferences.

Initially, there was resistance to Loansome Doc from some librarians, mostly because unaffiliated users were a new audience for them to serve. They had to decide who they would serve, if and how they would bill for the service, and how they would collect associated fees. Dr. Lindberg spoke at several librarian conferences to hear their concerns and to share his reasoning for wanting such a valuable content delivery service. His interactions with rural physicians during his years at the University of Missouri, Columbia provided firsthand insight about the need and usefulness of Loansome Doc.

2.1.2. Internet-based Access

Under Dr. Lindberg's leadership, NLM modernized other resources and tools to "fundamentally [change] the way biomedical knowledge and health information is collected, organized, and made available for public use" [6]. Health providers and scientists gained new or improved access to medical literature via PubMed and PubMed Central and to clinical trials and their results via ClinicalTrials.gov. The general public became a significant NLM user group once NLM's databases became freely available via the Internet. In 1998, NLM launched MedlinePlus, followed by MedlinePlus en español in 2002. These companion Internet-based resources for patients and their

families offer free and up-to-date information about diseases, conditions, and wellness issues in understandable language.

To inform user groups about these resources, NN/LM sponsored or conducted hundreds of exhibits annually at state, regional, and national professional and scientific meetings for health professionals, researchers, and librarians. The exhibits increased NN/LM's visibility while identifying NLM as a leader in biomedical information technology research and a developer of information systems [7]. RMLs also embarked on initiatives to add public libraries and community organizations to NN/LM and to train these groups about NLM Internet resources as authoritative sites for the public. By 2015, more than 6,000 academic health sciences libraries, hospital libraries, public libraries, and community-based organizations had joined NN/LM in its mission to bring high-quality information to health professionals and the public--regardless of location, socioeconomic status, or access to computers and telecommunications, putting NN/LM in a solid position to "bring the message about NLM's free, high-quality health information resources to communities across the nation" [5].

2.2. Community-based/Underrepresented Populations Collaborations

Engaging communities, especially minority and underserved populations, to learn more about their personal health through collaboration with and training by librarians was a shared value of Dr. Lindberg and NN/LM. Many NN/LM outreach initiatives focused on specific populations, such as unaffiliated health professionals (e.g., public health and rural health care professionals), community-based organizations, underserved minority communities, and non-medical librarians. With NLM funding, health science librarians partnered with communities to assess their information needs, learn about their political structures and health beliefs, and conduct - in concert with the communities - activities targeted to address the identified needs.

2.2.1. Public Health Partnerships

At its core, the initial target audience of NN/LM outreach to underserved and rural health professionals was physicians who did not have access to a medical library. The information needs of physicians were better understood than for most other health professionals. Access to the clinical literature through NLM tools and services was well suited to meet many of those needs. There was a good alignment between the needs, services, and tools, and audience. During the 1990s, outreach to other segments of underserved health professionals increased, e.g., the public health workforce - at the local level, as did awareness that the information needs of these diverse groups were less well understood.

The Partners in Information Access for the Public Health Workforce (Partners), a multifaceted collaboration, had its origin in a 1994 request to Dr. Lindberg from the Assistant Secretary for Health, Department of Health and Human Services, for help in improving public health access to and use of the emerging National Information Infrastructure. Formation of the partnership was recommended in an influential report from a meeting held at NLM in 1995. The meeting and the report reflected a shared sense that more was needed to adequately serve the diverse needs of public health professionals [8]. Several government agencies and professional organizations and associations came together under the auspices of NLM and the U.S. Center for Disease Control (CDC) to share information and resources. The Partners compiled resource guides and provided

training in finding and using information resources to public health staff to support informed practice.

The Partners enabled public health entities to learn about the resources and services of NLM and to make them known to their members and constituents. Also, many librarians were trained through the Partners in the diverse and complicated information needs of the public health workforce. This collaboration was at the core of what made the Partners successful.

2.2.2. Public Health Department Connections

Parallel with the development of the Partners, in the late 1990s, the potential of connecting computer networks for communication and information access was beginning to be realized. One example of this at the local level was a project to connect local health departments in Washington State to the state health department and the Internet. The project officers saw this as an opportunity to piggyback on a technology project and use it to train public health staff to more readily incorporate access to information, data, health guidelines, and other resources. The CDC and NN/LM were brought together through the Northwest Center for Public Health Practice, based at the University of Washington (UW), to coordinate and offer training at local health departments, once technological connections were established. The training sessions also provided an opportunity to conduct information needs assessments of segments of the public health workforce at the local level [9].

In 2010, the New England Region (NER) of NN/LM received funding to create a digital library tailored to public health. Seven public health departments were provided free digital access to licensed electronic resources. The supporting librarian team learned Internet access, hardware availability, online searching training, free full-text access to licensed resources, and support from upper leadership were all needed to facilitate evidence-based decision making by public health workers [10].

The NER-sponsored public health information access digital library project led to the creation of a customized digital library of no-cost full-text journal articles and books for state public health departments, first in New England and the state of Colorado. In addition to access to evidence-based resources, online searching classes, and searching consultation services were provided. An interlibrary-loan network was also established to obtain items not provided by the digital library. The digital library grew in type and quantity of full-text resources and databases and expanded its reach to other state public health departments.

2.2.3. MedlinePlus Go Local

At the 2010 Annual Meeting of the U.S. Medical Library Association (MLA) in Washington, D.C., U.S., a bittersweet celebratory gathering, including Dr. Lindberg, was held to sunset the Go Local projects funded by the NLM [11]. During the ten-year period of Go Local, more than 30 libraries and library consortia had developed Go Local websites.

Go Local was created by NLM in 2001 as a vehicle for linking users of the MedlinePlus consumer health information site to and from local quality health service and locator information. The project, overseen by RML programs across the country, provided libraries and library consortia with start-up funds for outreach to community-based organizations and local health agencies. The project provided "one-stop shopping" for access to nationally applicable information from MedlinePlus connected to and from

essential state and local health and human services-related resources. This project advanced connections with communities, public health departments, and other agencies supporting health information needs. The Go Local projects also created a community of practice among the Go Local sites. Site personnel met regularly to hear updates and share engagement strategies.

The Southeastern Atlantic (SEA) Region of NN/LM was a hotbed of Go Local sites, with seven Go Local projects funded, including the original prototype, NC Health Info. Each project reflected the unique characteristics of its state or home institution. For example, the Health Sciences and Human Services Library at the University of Maryland-Baltimore focused on assessing community health information needs, and then building relationships with community organizations and information providers across the state. The site was launched with a gala ribbon-cutting ceremony attended by local politicians, community members, NLM staff, and public health officials. Then Baltimore Health Commissioner, Dr. Joshua Sharfstein, thanked the Maryland Health Go Local team on behalf of the beneficiary citizens of Maryland.

The expense of sustaining the Go Local projects, and the growth of access to rapidly updated local health service information via Internet search engines and Internet-based health information sites, impacted the use and future need for this program. The Go Local websites served as models for other health information websites. There were many lessons learned about partnering with community-based organizations and with talented colleagues at NLM and across the country on a project. Many participants consider Go Local the most worthwhile project in which they have been involved. NLM's decision to cease support for Go Local is an example of Dr. Lindberg's willingness to let data about usage, sustainability, competition, and cost overrule his personal preferences.

2.2.4. Information Prescriptions (Rx)

Dr. Lindberg's understanding of the power of doctor-patient trusted relationships led him to encourage the use of information prescriptions. As he knew first-hand, many patients respond to a medical order from their provider. Using this same premise, if a provider issued a written order for information, Dr. Lindberg felt patients would be more likely to go to a library or online to obtain health information related to their conditions.

The NLM Information Rx initiative was officially launched in partnership with the American College of Physicians in New Orleans, Louisiana, on April 22, 2004 [12]. Dr. Lindberg introduced the concept and encouraged his medical colleagues to embrace it and refer patients to quality information, written for the lay person and delivered online via NLM's MedlinePlus. NLM created "prescription" pads with the MedlinePlus URL and space to notate the condition to be researched. The pads were small enough to fit into provider pockets for easy access.

Promotion of the Information Rx initiative was performed by NN/LM. Each region publicized the no-cost availability of the Rx pads to its members. Network librarians informed providers within their institutions and assured them they would be willing to assist patients with filling the information prescriptions. Professional library associations spread the word about the Information Rx pads so patients going to public libraries would be assisted by librarians familiar with the concept.

The Tompkins-McCaw Library at Virginia Commonwealth University received special NLM funding to identify barriers related to issuing information prescriptions at its clinical Women's Health Center located in Richmond, Virginia. Center providers were educated about the initiative and were eager to participate. Despite the initial

eagerness, time constraints with patient visits often did not provide the chance to explain the concept and issue the prescriptions, or providers simply forgot to do so [13]. These factors were common barriers. When not a significant issue in the many settings where the project was successfully deployed, Information Rx proved Dr. Lindberg correct in his belief that providers can influence patient behavior.

After several years, NLM phased out the printed Rx pads in favor of experimenting with a protocol for direct connection from electronic health records. This service, called MedlinePlus Connect, is still in heavy use today. Several librarians partnered with their electronic health record departments to add quality health information to patients' personal health records and to create an automated way for providers to issue health information via patient visit summaries. The concept of provider referrals influencing patient information-seeking behavior, highlighted by Dr. Lindberg's Information Rx efforts, proved to be a long-term success.

2.2.5. Symposium on Community-based Health Information Outreach

An example of Dr. Lindberg's commitment to programs designed to improve the quality of life and eliminate health disparities is NLM's support for the 2004 Symposium on Community-based Health Information Outreach, proposed by the University of Utah and the New York Academy of Medicine. The Symposium encouraged participants to increase their awareness of barriers to accessing reliable health information and to consider potential innovative solutions designed to improve information access, especially for traditionally marginalized populations [14].

The Symposium was held at NLM's Lister Hill Center on December 2 and 3, 2004, and was streamed live to a worldwide audience. The two-day event included 150 participants from various backgrounds and experiences, including librarians, community-based workers, and evaluation specialists. The Symposium's primary goals were to discuss the use of information and communication technologies to develop new community engagement models and to demonstrate how using these new technologies could increase the capacity of health sciences libraries to deliver programs and services beyond their traditional boundaries. The Symposium also was an opportunity to explore new ideas in consumer health information outreach, to consider increasing access to health information through community-based organizations, and to discuss NLM's current and future efforts to reduce health disparities for all underrepresented communities, with a particular focus on American Indian/Alaska Native populations.

The Symposium planning committee consisted of representatives from NLM and representatives from several RMLs. The program included keynote speakers, papers, and posters. Presenters focused their discussions on the importance and impact of NLM's outreach, methods for assessing complex outreach activities, strategies librarians can deploy when engaging with community-based organizations, and recommendations on next steps for supporting outreach to underrepresented communities.

The Symposium concluded with a consensus NLM and NN/LM should continue their outreach to underrepresented and traditionally marginalized communities and to work toward developing partnerships and collaborations with community-based organizations, as key strategies to extend the reach of NLM and NN/LM. Participants encouraged NLM and NN/LM to continue investing in the design and implementation of projects considering complex cultural structures, as well as recognizing the deep-seated challenges faced by communities with the most need [15].

2.2.6. American Indians/Alaska Natives

As a result of a 1995 review of NLM's outreach programs, NLM determined more attention was required to engage American Indian/Alaska Native communities. Subsequently, NLM funded several important programs, including the Tribal Connections projects, and NLM's exhibition "Native Voices" about Native beliefs and practices regarding health and wellness. Dr. Lindberg's influence and vision was central to increasing NN/LM outreach to American Indians/Alaska Natives.

2.2.6.1. Tribal Connections

NN/LM's health information outreach initiative, known as Tribal Connections (TC), was a constellation of collaborations among American Indian/Alaska Native communities and health science libraries. The TC program was initially designed in three phases - TC I, II, and III - which ran between 1998 and 2003. These first three phases were implemented by the NN/LM Pacific Northwest Region RML (PNR), located at the University of Washington's Health Sciences Library, with funding and partnership support from NLM. The goal of TC I was to improve access to the Internet for 16 Alaska Native/American Indian communities in the northwest United States. PNR worked with each community to identify what was needed to improve access and use of health information. The tribes emphasized Internet connectivity as their number one need. Without reliable connections, the growing numbers of authoritative Internet resources were simply out of reach. With PNR funding, each community developed local strategies for improving connectivity through a community-based approach to project planning and implementation [16]. Community members participated in NN/LM training on digital health literacy and consulted with NN/LM about culturally relevant health information. TC II focused on American Indian communities in the southwest. TC III implemented community-based approaches to increasing the use of reliable health information through training and education in the states of Idaho, Oregon, and Washington.

In 2001, TC IV, also known as Tribal Connections Four Corners (TC4C), was created with heavy influence from the initial TC program, as well as the Tribal Health Connections Project, funded by the Bill & Melinda Gates Foundation. At the time, the TC4C project was the largest collaborative outreach project designed to engage American Indian communities in NLM's history and included the involvement of three NN/LM regional offices, the MidContinental Regional Medical Library (MCR) at the University of Utah, South Central Regional Medical Library (SCR) at the Houston Academy of Medicine--Texas Medical Center, and the Pacific Southwest Regional Medical Library (PSR) at University of California, Los Angeles. Four Resource Libraries joined in the effort, including the University of Arizona, University of New Mexico, University of Colorado, and University of Utah. TC4C made funding available to organizations, including public libraries serving American Indian populations, and it offered training on the use of NLM resources.

Two important features of the TC projects were increased community engagement and infrastructure improvements. Early in the project, staff assessed the technology needs of the participating tribes, which resulted in improving access to the Internet through upgrades to computers and connectivity. The project also increased the number of partnerships between tribes and organizations interested in sharing technology and infrastructure resources. Another important achievement was funding dedicated to tribal community outreach coordinators and professional personnel who worked to implement the project's goal of increasing access to health information to participating communities.

These coordinators focused on developing connections, trust, and familiarity to improve their encounters with tribal communities. The combination of these areas of outreach and technology resulted in an increase in community members' proficiency in the use of computers and interest in using the Internet to find NLM resources to answer health-related questions. The TC project also deepened NN/LM's understanding of culturally appropriate health information outreach with American Indian/Alaska Native communities [17].

2.2.6.2. Native Voices Healing Totem

In September 2011, the University of Washington Libraries and the Native American Land Conservancy celebrated the blessing of a beautiful healing totem commissioned by NLM in honor of the new NLM exhibition focusing on Native views and definitions of health and illness. Lummi Indian master carver Jewell Praying Wolf James, a world-renowned master carver of totems or healing poles, crafted NLM's healing totem. Mr. James is the lineal nephew of Chief Seattle (for whom the city was named), and the head carver for the House of Tears Carvers of the Lummi Indian Nation in Bellingham, Washington. The totem blessing and celebration, held at the Seattle Center on September 11, 2011, launched a series of totem blessings attended by NN/LM representatives in cities and tribal communities across the country, as the totem traveled to the East coast, with final placement in front of NLM on the National Institutes of Health campus. In its permanent home, the totem became a dramatic focal point of the NLM exhibition, *Native Voices: Native Peoples' Concepts of Health and Illness*.

In 2011, the University of Pittsburgh Health Sciences Library System became the RML for the states of Delaware, New Jersey, New York, and Pennsylvania. In starting a new RML, Renae Barger, Executive Director, was recruiting staff when asked by NLM to attend blessings and write blog postings at two stops on the NLM Healing Totem's journey to tribal sites in New York. Coincidentally, incoming Outreach Coordinator, Kate Flewelling, was preparing to move to Pittsburgh from Syracuse, N.Y., minutes from the Onondaga Nation Reservation, one of the journey stops. Even before her official start date, Flewelling had her first outreach assignment. She witnessed the Opening Ritual, which included a regular meeting of the Chiefs' Council in the Nation's language and an introduction to the Totem from Jewell Praying Wolf James. As a new outreach staff member, Flewelling learned the importance of listening as a key component of outreach and community engagement.

A few days later, Barger attended a two-day ceremony at Arrow Park, N.Y., the home of another Healing Totem, dedicated by the same master carver in honor of the victims of September 11. In 2002, the Lummi Indians dedicated the Healing Totem and marked Arrow Park as a special place of healing. Since then, Arrow Park has been a site for an annual tree planting to honor 9/11 victims. It is a dedicated site of professional training programs about bereavement, suicide prevention, and post-traumatic stress disorder. Barger remembers learning about NLM's Healing Totem's journey and the meaning behind its markings. The sense of respect and pride, and the overwhelming appreciation of Dr. Lindberg for driving this important effort to showcase and preserve cultural traditions of healing practices were evident.

2.3. Influence on NN/LM Services

Dr. Lindberg long recognized the leadership role of RMLs in guiding changes and improvements to NN/LM services. In this section, three health science libraries, serving as RMLs during Dr. Lindberg's tenure, describe important initiatives NLM supported enabling RMLs to: 1) build capacity for evaluation by NN/LM network members and RMLs; 2) use NN/LM evaluation tools and resources to pilot and communicate the impact and results of a new decentralized RML; and 3) foster the role of librarians in eScience.

2.3.1. Support for NN/LM Evaluation

In the mid-1990s, outreach to underserved populations became one of Dr. Lindberg's highest priorities for NN/LM. Acknowledging many NN/LM librarians sought guidance about ways to evaluate their outreach programs, NLM conceived, funded, and oversaw a specialized outreach planning and evaluation study.

NLM's Office of Health Information Programs Development division provided leadership for the study, conducted by the PNR. A group of 18 national experts advised the evaluation study, to add their multi-disciplinary perspectives to library outreach evaluation practices. White papers authored by several of the advisors provided a theory-based framework for the resulting NN/LM evaluation guide: *Measuring the difference: guide to planning and evaluating health information outreach* [18]. This 130-page guide, first published in 2000, is still considered a primary evaluation resource of the NN/LM. About 4,000 copies have been distributed to U.S. and international organizations, such as libraries in hospitals, medical centers, and universities, as well as departments of public health, faith-based organizations, and all kinds of non-medical libraries.

Between 2001-2015, NLM funded and supported the Outreach Evaluation Resource Center (OERC), based at the PNR, to help NN/LM members and RMLs collect, understand, and act on information about their projects to plan and improve their programs and adapt them to changing environments. OERC developed and published a booklet series to supplement NN/LM's evaluation guide [19-21]. The booklet series simplified the evaluation process described in the guide, to make it less overwhelming to anyone with minimal background in research and evaluation. The booklet series was last updated in 2013, and it is available in print or online at no cost. Roughly 3,000 print copies have been distributed globally. NLM continued to fund a National Evaluation Office at the PNR until 2021.

2.3.2. A Decentralized Regional Medical Library

The University of Utah's Spencer S. Eccles Health Sciences Library's (EHSL) proposal for the MidContinental Region (MCR) of NN/LM was accepted in 2001; it focused on a technology-based, decentralized implementation of resources, including staff. Unlike most other Regions in the NN/LM, each state in the Region had only one Resource Library, which hired a local librarian to get to know the people, communities, and organizations in their state to match appropriate NLM resources with their unique health information needs. This resulted in greater breadth and scope of outreach activities, deeper relationships with partners within each state, and a significant pool of individuals with whom to engage in project development and funding applications. Prior, all RMLs had a centralized operations office. The EHSL proposal distributed the technology and

the money to the state Resource Libraries, thus providing them with an immediate benefit of MCR participation and ensuring their work commitment.

Discussions of the distributed model among the Resource Library Directors (RDLs) began as early as 1993, while the RML functioned in the typical centralized model at the University of Nebraska. All RDLs were keenly interested in the potential for working together in a new way, utilizing new technologies to support communications and collaboration. Dr. Lindberg was enthusiastic about the ideas presented in University of Utah's proposal for two reasons. First, this new model was dependent on applying technology to aid communication, planning, and outreach to each state. Second, he was convinced a model based upon greater collaboration among key libraries would better forward NLM's goal to bring reliable health information to more people.

Regular meetings and communication with RDLs and their MCR librarian staff allowed for strategic program planning, collaboration, and program evaluation resulting in clear expectations, goals, and achievements. The experience with program evaluation fed into the growing movement among librarians to use data for decision making, demonstrating their value to administrators, and improving their research skills. The "Measuring Your Impact" workshop developed by staff at MCR and PNR taught hundreds of librarians to collect data to evaluate their resources and services. A website was developed to collect financial data and provide means to measure cost-benefit-analysis and return on investment [22].

2.3.3. eScience

Spurred by NLM's advances in bioinformatics and policies for open science to drive scientific discovery, NN/LM embarked on new initiatives, such as eScience programs, promoting the librarians' role in research data management. NER developed the first eScience program.

Recognizing the need to address eScience as a field of practice intersecting with diverse constituent groups such as library specialists, IT specialists, and researchers, NER sponsored the first eScience Symposium in 2009. It convened librarians and information scientists from basic sciences, health sciences, medical centers, and general academic libraries to explore the various roles eScience could entail for the community. Based on feedback and enthusiasm displayed by attendees, work began to assess needs and develop resources to enhance basic science knowledge of librarians, while also gathering resources focusing on the principles of eScience best practices. An assessment of biomedical and science librarian eScience learner and user needs was conducted to compile and organize an online portal assembling the tools needed to address eScience capacity building. Working with key participants in NER, advisory and editorial boards were established, and the eScience Portal for New England Librarians was born [23].

Subsequent symposia, professional development programs, and extended eScience Boot Camps were established to continue capacity building, expand data literacy, and advance partnerships and collaborations. Through these programs, NER became the academic home for New England area librarians and consortia partners with a shared interest in fostering the role of librarians in data science research initiatives.

NER eScience efforts served as a model for addressing the research data management needs of librarians and researchers in other NN/LM regions [24]. Through NLM's invaluable funding support, NER's development and implementation of its eScience program and community of interest equipped network members with a new understanding of eScience and the roles librarians play in helping their researchers

manage, preserve, curate, and share data. By 2010, eScience initiatives were a required program element in NLM's Request for Proposals for RML programs in 2011-2016.

3. Summary

The depth and breadth of Dr, Lindberg's influence upon NN/LM is hard to quantify, as he was either directly or indirectly promoting access to the medical literature and libraries to health care providers and the public to improve the nation's health. This chapter offers some key highlights of his extensive involvement and guidance. It is by no means an all-inclusive collection. There are many more NN/LM outreach activities and efforts not reflected in this chapter. Readers are encouraged to consult the various journal articles listed in the references to learn about others. In addition, NN/LM did not perform outreach initiatives in isolation, but often partnered with NLM's Specialized Information Services Division, Office of Health Information Programs Development, and National Information Center on Health Services Research and Health Care Technology. Through such internal collaborations, more citizens benefited from NLM's outreach activities under Dr. Lindberg's expansive and informed direction.

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BITNIS – Bridging the Information Gap Before the Web

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Abstract. Before the modern internet and World Wide Web drastically simplified our access to scientific information, accessing the authoritative information of the National Library of Medicine (NLM) from outside the U.S. was for many very difficult. Compared to the totality of people with access to computers globally at the time, only a privileged group of biomedical researchers and practitioners could afford this access. The NLM was making great contributions developing products and collaborations to reduce the information gap for many underserved communities. This article describes a remarkable initiative started from the other end, underserved information users creating a solution to help the international community reach the NLM resources. Donald A.B. Lindberg M.D., the NLM Director and health informatics pioneer, believed in letting users guide the NLM down its path of service. The BITNIS project is a successful example of his leadership philosophy at a turning point in health informatics history.

Keywords. U.S. National Library of Medicine, Donald A.B. Lindberg M.D., Health informatics history, bibliographical information, computer networks, electronic information services

1. Introduction

Donald A.B. Lindberg M.D., the U.S. National Library of Medicine (NLM) Director and health informatics pioneer, understood that the success of NLM's efforts depended not only on their value to the nation, but also to the rest of the world. Before the Internet arrived at the NLM, remote access to its databases from outside the U.S. was mostly reserved for a privileged elite. Dr. Lindberg's vision and unrelenting pioneering spirit changed that forever.

Through its long history, the NLM has evolved constantly to offer more and better services and products to a growing audience. To that end, Dr. Lindberg led the development of many innovations that revolutionized health informatics. This is the story of one of those innovations, which, although not well known, had a significant impact internationally.

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2. Information Access, a Coveted Privilege

In the mid-1980s, Andrés Stutzin invested a few years as a visiting fellow at the National Institutes of Health (NIH). During his temporary research appointment as a visiting fellow with the NIH National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK), he and his colleagues benefited from the NLM's authoritative bibliographical information almost daily. At his lab, in the heart of the NIH Bethesda campus, his access to the NLM databases laid just steps away at his personal computer. He could also walk to the NIH Library or the NLM itself when he wanted assistance formulating a literature search strategy or submerge himself in the scientific literature. Usually, full-text articles arrived at his lab in government-issue manila envelopes not long after requesting them from one of the libraries. As a research biologist, he marveled at the enabling power of NLM resources for his scientific work. As a medical doctor, he understood the immense value of NLM information to support the core goals of medicine.

In 1987, after resuming his academic and research work in Chile, Stutzin had to face the stark reality of the "information gap" that plagued developing countries and other disadvantaged world regions. The Medical Library at his workplace in the Faculty of Medicine of the University of Chile had a subscription to MEDLINE on CD-ROM, but the information was relatively stale and did not cover the full MEDLINE content. Remote access to MEDLINE from the NLM and other commercial venues was available, but budgetary and other practical constraints made that access hard to use. Journal subscriptions were limited and accessing full-text literature often took significantly more time and effort. At the time, this scenario was not uncommon for international fellows returning home after holding temporary positions at the NIH.

At his institution, Stutzin was a member of the Medical Informatics Commission (CIM, for its name in Spanish), a faculty-level advisory group focused on enhancing information technology-based resources. Among his contributions in this role, Stutzin helped modernize and grow the campus-wide computer network infrastructure and helped coordinate its interconnection with a larger academic network that spanned several local universities. Seeing the power of networks to boost collaboration and host remote information services, he teamed up with Víctor Cid, a CIM advisor, to investigate options for enabling access to NLM databases through this infrastructure. At the time, Cid was with the Faculty of Physical and Mathematical Sciences of the University of Chile and led the engineering team responsible for the national academic network. Their research turned into a quest to make remote access to NLM information resources more available and affordable to support research, education and medical practice in Chile, and beyond.

3. NLM Options and Realities

In 1987, the world was experiencing a rapid growth of "personal computing". The trend originated in the late 70s and contributed to the development of many isolated, independent networks of interconnected computers around the globe. Many of them grew in a "collaborative" fashion. The Internet was young, and, although famous, it was still just one of the many computer networks in existence. The World Wide Web was still a few years in the future, but services like electronic mail had already become popular within and between many computer networks, and via independent commercial venues [1]. It was also a time of "big iron", room-size mainframe computers that large

organizations used to conduct business and provide services to multiple users in a centralized manner [2].

At the time, the mainframe computers that hosted the database services of the NLM could be accessed by thousands of remote users through dozens of telephone lines and several commercial packet network service providers. However, these host computers were not connected to computer networks. Dr. Lindberg was never shy about trying new technologies, but to be adopted, new technologies had to demonstrate their usefulness to fulfill a need in the context of the NLM's mission. The NLM operated on the principle that "technological innovation must be an aid to improved medical research, education and practice" [3].

The Medical Literature Analysis and Retrieval System (MEDLARS) of the NLM had for long been considered a leading bibliographical information resource for biomedical researchers and practitioners worldwide. MEDLARS data was accessible in different ways, but interactive access to MEDLINE (MEDLARS online) was the preferred access method for users needing timely access to the most up-to-date and complete data. International users who wanted to conduct their own database searches also had a few options: access directly from computer terminals connected to mainframe computers that held copies of the NLM information resources at a few international locations; remotely through a computer program called Grateful Med (GM); or via CD-ROM subscriptions. Remote access without GM was also possible, but GM was by far the preferred method (Figure 1) [4-5].
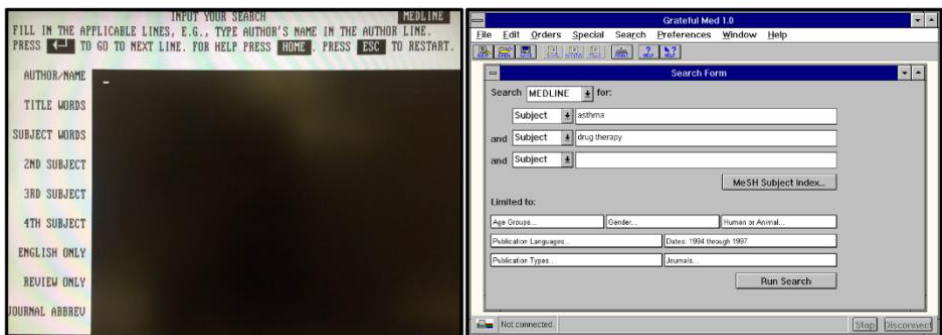

Figure 1. MEDLINE search design screens of Grateful Med for DOS version 4.0, circa 1988 (picture courtesy of the Library of Congress), and GM for Windows version 1.0, circa 1997 (picture courtesy of the NLM).

Remote access to MEDLINE with GM could be achieved a few ways, and generally involved a personal computer, modem and telephone line.[3] Users could place an international phone call with their computers to the NLM, a local or long-distance call to the closest International MEDLARS Center (IMC), or a call to a local commercial packet network service (e.g., TELENET or TYMNET) and use that service in turn to connect to the NLM [6]. In practice, these options were feasible only to international users who were fortunate enough to be close to a MEDLARS Center that hosted local copies of the NLM's databases or could afford the expense of long-distance or international phone calls and/or the packet network service. Telephone services in most locations were metered, and packet networks typically billed by time and data volume

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[3] To those of us who witnessed that time, the unique squeaks, squeals, and white noise blurs of dial-up modems were carved indelibly in our auditive memory.

transferred. Also, in many international locales telephone service was not capable or reliable enough to support data communications.

But those were not the only barriers. Accessing the NLM databases was not free, therefore users needed to obtain a MEDLARS user account from the NLM or a ICM and pay a metered on-line access cost. The NLM used the proceeds mainly to offset the telecommunication costs required to provide the service and pay data suppliers. For instance, a remote MEDLINE search session from outside the U.S. could cost a user US$25 or more in 1990 dollars, mostly due to telecommunications costs [7]. As a result of these costs and technological barriers, remote access was often prohibitive for many remote users, especially, although not only, in the developing world.

CD-ROM subscriptions were popular at the time, although they only provided access to a subset of the NLM content, and the currency of the data was necessarily a few months behind. Unfortunately, CD-ROM subscriptions, which were available from a few commercial vendors, sometimes were also unaffordable for individuals and small organizations in developing countries. Subscription costs were in the order of $2,500 per year, plus shipping costs, and required equipment that at the time was relatively expensive to obtain and maintain [8]. Also, shipping CD-ROMS to some remote locales at that time was harder than it is today.

4. Bringing NLM Closer to International Users

In 1966, the NLM started establishing collaborative arrangements with foreign organizations to respond to requests for using the NLM databases from users outside the United States. Through quid-pro-quo/Memorandum of Understanding (MoU) agreements with national entities, the NLM supported the creation of several IMCs, which numbered 17 in 1987 and reached 20 in 1997, in as many countries. The NLM provided the IMCs copies of MEDLINE and other resources and required software, usually on magnetic tapes, technical documentation, and training. In turn, the IMCs provided bibliographical services regionally, service evaluation and technical feedback, and sometimes other services for the NLM, such as indexing international journal articles. The MEDLARS Centers greatly enhanced the reach of the NLM products and services to the international community and helped the NLM enhance its products and services [3].

Since the early 80s, an IMC was available at the Pan American Health Organization's (PAHO's) Regional Medical Library for Latin America and the Caribbean in Sao Paulo, Brazil (BIREME, for its Spanish acronym)[4]. BIREME is located at the heart of one of the main Brazilian universities and plays an important role satisfying the biomedical information needs of that university and other health organizations and professionals throughout Latin America and the Caribbean. This library also contributes valuable technical and other innovations for the development, management, and provision of biomedical information services in a manner that is adequate for the cultural, social, and economic realities in the served countries. BIREME also provides inter-library loan services in the region [9].

However, in the 80's, accessing MEDLINE at BIREME remotely from many places in Latin America was often as difficult as accessing it directly from the NLM. Metered

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[4] PAHO is the office of the World Health Organization (WHO) for Latin America and the Caribbean.

and low-quality telephone services in many locales, and the scarce availability of packet data networks and dedicated telecommunications links to BIREME, made accessing this resource challenging and often unaffordable. There were also language barriers and service support challenges. BIREME's region of service includes 51 countries and territories and five different official languages. BIREME also had to balance its priorities of serving the needs of its parent organization and others in Brazil, and users throughout the region. BIREME is an outstanding organization, but some of its users felt that its broad responsibilities sometimes seemed to require more resources than BIREME had available.

MEDLINE on CD-ROM made great strides towards satisfying information needs for many international users, but it was necessarily an imperfect substitute for direct access to the NLM databases.

5. The Gift of International Collaboration

PAHO and the NLM had a MoU that enabled them to collaborate in a variety of information programs since the late 70s [10]. In 1997, Dr. Lindberg learned through PAHO about the effort initiated by researchers of the University of Chile to explore the feasibility of accessing the NLM resources through international computer networks.

The NLM Director was very familiar with the enduring information gap issue, which seemed to have worsened over the years due to the technological disparity between developed and developing nations. For a long time, Dr. Lindberg worked towards positioning the NLM as a strategic resource for addressing issues such as health inequality, global health and maximizing the productivity of biomedical sciences, all of which required access to and sharing of reliable and updated scientific information at a global scale. However, reducing the information access barriers internationally and extending the NLM's reach beyond what was possible through IMCs and CD-ROMs was a monumental challenge.

Over time, the Chilean researchers engaged PAHO and proposed to the NLM a solution that involved NASA, IBM Corporation, the University of Maryland at College Park, the NIDDK, the Division of Computer Research and Technology (DCRT) of NIH, and the University of Chile. Dr. Lindberg appreciated the merits of the proposal, but the Chilean experiment came with non-trivial risks. In addition to the multi-institutional coordination challenges, the plan involved interfacing the NLM computers with technology that was foreign to that in use at the NLM and possibly experimenting with unproven ways to recover service costs from database users, among others.

However, Dr. Lindberg could see through and beyond those risks and focused on the opportunities that the proposed remote access mechanism offered to further extend the reach of the NLM services globally. He instructed the NLM Director of International Programs to support the Chilean experiment, in the hope that it could inform future efforts.

6. The Power of Email

Many computer networks spotting the globe in the 80s were mutually incompatible. Within each network there was great creativity and constant innovation, but their

heterogeneity made interconnecting them challenging due to competing and incompatible network protocols, architectures, services, and equipment, among others. However, all computer networks offered some kind of asynchronous messaging capability that enabled users to exchange electronic correspondence within a network and often between them.

The features and capabilities of the email services on those networks varied widely, but at minimum it allowed its users to send each other text communications in a reliable way. In most cases, email was resilient to poor communications infrastructure due to its "store-and-forward" design. Email messages usually hopped from one network node to the next on the path to their destination, where they were stored and then forwarded to the following node along the way. If an intermediary network connection was interrupted or performing poorly, the messages were automatically retransmitted by the preceding node until a successful transmission was completed. Due to varied quality and features of data links, which often involved regular commuted telephone lines, an email could take seconds to days to arrive to its destination, but the network protocols guaranteed the integrity of the message on delivery, unless the transmission was impossible after some retransmission limit. Email has evolved over the years, but the essentials remain the same [11].

In the late 80s, the NLM and PAHO were already very familiar with the advantages of electronic mail, which was available to them from government and commercial providers. Naturally, email was already being used in some cases to provide limited human-assisted database searching services to distant users. However, the University of Chile researchers envisioned a service that was automatic, could handle a large number of service requests, and that was easy to use and affordable to its users. Regardless, the hardest problem was the huge telecommunications gap to Chile.

7. Bridging the Gap

The solution came from a fortunate convergence of resources and relationships. At the time, the University of Chile managed several national computer networks, and had developed an expertise on interconnecting dissimilar computer and information systems. The main network was BITNET (Because It's Time Network), which linked IBM mainframe computers from several universities [12]. However, the BITNET network in Chile was not interconnected with its equivalent in the United States, as the cost of a high-speed, dedicated telecommunications link between Chile and BITNET was at the time economically unfeasible.

The University of Chile had a good collaborative relationship with NASA, which had an installation close to the capital city of Santiago. They learned about the interest in interconnecting University of Chile networks with others in the US and offered access to a dedicated satellite link from Santiago to Goddard Space Flight Center in Greenbelt, MD, a few miles away from the NIH campus. The link was used for NASA operations part of the day and was sufficiently fast for email communications and more. Through a collaborative agreement, NASA enabled the University of Chile to use the link a few hours per day for this experimental project. This solved the problem of reaching the United States, but an additional effort was required to reach the NLM.

Meanwhile, researchers from NIDDK on the NIH campus maintained a close relationship with their counterparts at the University of Chile and viewed this link as an opportunity to enhance their research collaborations. The NIDDK researchers sponsored

the link and engaged engineers from the Computer and Space Sciences Department of the University of Maryland (UMD) at College Park to coordinate the implementation of the data link to the Department of Computer Research and Technology (DCRT) at the heart of the main NIH campus in Bethesda. At the time, DCRT was already connected to BITNET and therefore the link enabled interconnecting Chile to BITNET in the U.S. A modem connection via a regular telephone line to DCRT completed the electronic bridge all the way from the NLM mainframe computer room all the way to the University of Chile.

To complete the solution, the Chilean researchers had to develop customized technology to enable the remote user access to the NLM databases. Given that the telecommunications solution only provided intermittent and relatively slow connectivity, the researchers designed a system that enabled processing MEDLARS database queries in "batch" form or off-line. Electronic mail was the natural choice as the transport mechanism to receive database requests from users and send results back, as email did not require permanent connectivity or high bandwidth and could handle the data volume of individual transactions.

8. BITNIS is Born

The Stutzin-Cid team implemented a gateway system that interconnected BITNET and the main NLM database server for the first time in 1988. The system emulated a librarian automaton that received emails with database search instructions from BITNET users, logged in to the server and conducted the requested search queries on the required database, captured the search results, optimized them, and sent them back to the requester via BITNET email (Figure 2).
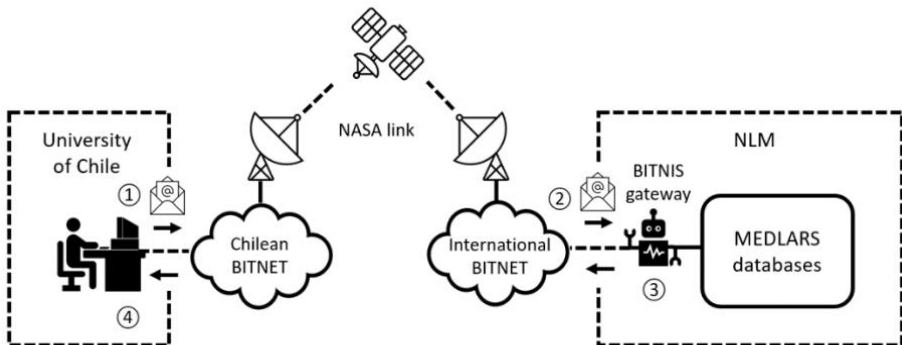

Figure 2. BITNIS functionality: (1) A remote user prepared a search with GM and sent it to BITNET in route to the NLM; (2) the email arrived to BITNET at NIH via the NASA link and the BITNIS gateway downloaded it from the NIH BITNET node; (3) the gateway conducted the requested database search, captured the results and set them back to the requester via BITNET email; (4) the remote user received the response email and could view the search results with GM. The gateway evolved to allow any users using computer networks interconnected with BITNET to conduct database queries, provided they had a MEDLARS user account registered on BITNIS.

This automatic gateway, called BITNIS (the acronym's meaning evolved over time, but it originally meant "BITNET to NLM Intercommunication System"), also had access control and accounting features that enabled billing users to pay the NLM for database online time. The gateway interacted with the NLM database server faster than a human could over a dial-up line, minimizing the on-line time expense for its users. There was no fee for using BITNIS itself.

Cid also developed "middleware" software to enable users creating a MEDLINE query with Grateful Med in their personal computers, and then embed the query in an email that was then sent to BITNIS for processing. The query language used by the NLM database system was complex and GM greatly simplified formulating searches via its interactive user interface, hence reducing the chances of errors. After BITNIS had replied with search results, the "middleware" also enabled users to view the results with Grateful Med and refine the search if necessary [13-15].

Soon after inception, BITNIS started to process dozens of database queries per day from University of Chile's faculty, students, researchers, and librarians, in addition to clinicians from its university hospital.

9. BITNIS Expansion in Latin America

The experimental gateway proved to be effective. Users from the University of Chile could use MEDLINE without incurring telecommunications costs, enabling many more of them to access the NLM information. The University maintained a deposit account with PAHO, which in turn paid NTIS for the use of the NLM databases in the United States. Very soon, the University started to receive inquiries from other universities and research institutions along the country, and pressure started to build up to expand the service.

Given the success of the Chilean experiment, Dr. Lindberg saw the opportunity to use BITNIS for extending the reach of the NLM services to other underserved communities around the world. With support from PAHO and the University of Chile, the NLM extended the service to any Latin American country that could access international academic networks and the BITNIS gateway via email. Initially, the service operated with a single MEDLARS user account, but it was expanded to enable multiple accounts. Also, thanks to hardware donated by IBM corporation, the gateway was upgraded to support higher transaction rates and shorter service turn-around times. PAHO made special arrangements with the NLM and NTIS[5] so PAHO could administer MEDLARS user accounts for BITNIS access, and sponsor or charge users and pay NTIS for their use of the NLM databases.

First the service was expanded to other Chilean universities that had networks connected to the University of Chile. Meanwhile, the academic network continued to grow, which enabled adding more users from other universities and health organizations. Soon, networks in Argentina started to join in, some via their own connections to BITNET or other networks interconnected with BITNET in the U.S., others through connections to Chilean networks [16].

The value of the information access pathway that BITNIS opened had unexpected benefits: it provided an incentive for some national networks in South America to interconnect with each other and join international computer networks. In Chile, the

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[5] The National Technical Information Service, U.S. Department of Commerce.

National Commission for Scientific and Technological Research (CONICYT, analogous to the National Science Foundation in the U.S.) financed additional network infrastructure and soon the project did not have to rely on the NASA link anymore. The project results also encouraged PAHO to join BITNET and allocate resources for enhancing computer-based communications and collaborations for medical education in the region [13].

Additionally, the BITNIS expansion in Latin America provided an incentive to develop a collaborative user network. PAHO, the NLM, and CONICYT supported a BITNIS Regional Workshop in Santiago, Chile in May 1993. The event was attended by more than 60 BITNIS users, information technologists and other specialists from universities and other national entities from 10 countries. The meeting enabled the participants to share experiences, get training on searching MEDLINE and other NLM databases, and learn about other information services, technologies, and project opportunities. The meeting also provided the participants important networking opportunities that opened the door to other collaborations.

10. Global Expansion

In 1991, Cid joined the NLM and led the transition of the BITNIS gateway from experimental to a production service [17]. The gateway was upgraded from an IBM PC to a faster Sun Spark workstation with a faster network connection. Meanwhile, a collaboration with the National Cancer Institute (NCI) enabled remote access via BITNIS to PDQ (Physician Data Query), a cancer information resource also hosted at the NLM. The NCI maintained a network of collaborating health researchers and practitioners internationally, many of them in developing countries.

Interestingly, some health professionals in developed countries also saw advantages to accessing the NLM databases directly through computer networks and BITNIS. Soon, BITNIS started to process database queries for users in Germany, Switzerland, and Portugal.

After the fall of the Iron Curtain in 1990, countries that were part of the former Soviet Union faced hard challenges in their journey towards joining the rest of the world as independent states. In 1992, the Department of State (DoS) sought the NLM's help bringing access to authoritative health information to those countries as part of a strategic effort to establish friendly relationships with the new nations and provide humanitarian support. Dr. Lindberg saw BITNIS as the perfect tool to support this effort. The NLM collaborated with the DoS by devoting NLM resources to enable the access to MEDLARS from Confederation of Independent States (CIS) countries through BITNIS [18]. Joint teams from the NLM and DoS were deployed to CIS countries to provide connectivity, equipment and training to health and other national libraries in countries in Eastern Europe and Central Asia. Most libraries had remarkable library assets and experienced librarians, but poor or not functional telephone lines and information technology. Through this initiative, many national libraries in CIS countries were equipped with personal computers and other IT equipment and gained access to international computer networks and NLM information resources via BITNIS.

Around the same time, a non-for-profit organization called SatelLife had developed a communications service based on low earth orbit satellites to improve health communications in developing countries [19]. The initiative, called HealthNet, started to be used to provide access to the NLM information through BITNIS from Africa, parts of

Asia, and the Middle East. With support from the World Health Organization, users in Uganda, Zimbabwe, Malawi, Turkey, and other locations gained access to the service using small ground antennas pointed to the sky.

By February 1997, BITNIS served users in 56 countries (Table 1). That year, the number of user accounts in the system had grown to nearly 400. It is hard to estimate the actual number of end users benefitted by the service, as often accounts were shared among groups of users in their localities. For instance, a single account could be used by 20 or more users in a library setting. In 1996, at the peak of the service, the BITNIS gateway processed about 400 search requests per day.

Table 1. Countries using BINITS as of February 1997.

Africa:	Eastern Europe:	Latin America/Caribbean:
Egypt	Belarus	Argentina
Eritrea	Czech Republic	Chile
Ethiopia	Estonia	Belize
Kenia	Georgia	Bolivia
Malawi	Latvia	Brazil
Sudan	Moldova	Cayman Islands
Uganda	Romania	Colombia
Zambia	Slovak Republic	Costa Rica
Zimbabwe	Russia	Cuba
	Ukraine	Ecuador
Asia:		El Salvador
China	Europe:	Guatemala
India	Germany	Jamaica
Kazakhstan	Hungary	Mexico
Kirgizstan	Portugal	Nicaragua
Mongolia	Switzerland	Paraguay
Pakistan		Panama
Tajikistan	Middle East:	Peru
Thailand	Israel	Uruguay
Tibet	Turkey	Venezuela
Uzbekistan		

11. The BITNIS Legacy

Starting in 1996, users around the world could finally access MEDLINE through the young World Wide Web. The MEDLINE content was now also available in PubMed, an Internet-accessible service developed and maintained by the NLM National Center for Biotechnology Information (NCBI). However, the Internet remained elusive to underserved communities in many countries, and therefore BITNIS continued to play a role for some time. NLM gradually started to lift the access cost for some of its MEDLARS databases. By 1994, access to AIDSLINE, AIDSDRUGS, AIDSTRIALS, DIRLINE became free in support of the response to the HIV/AIDS pandemic. On June 26, 1997, in a Capitol Hill ceremony featuring Vice-President Al Gore, the NLM announced that MEDLINE became available to the world free of charge on the Internet through PubMed [20]. By then, the Internet was more widespread globally and the

BITNIS gateway started to see a marked traffic decline. At that point BITNIS had completed its mission and the service was discontinued. Shortly after, the legacy MEDLINE system was also discontinued. It was the end of an age in the history of the NLM, and the beginning of a bright new one.

The benefits of BITNIS extended beyond connecting underserved communities to quality biomedical information. The implementation of the service in multiple countries not only allowed interconnecting people with the NLM, it promoted technological innovation by providing incentives for network development and inter-networking, hence helping speedup the inclusion of many in the Internet revolution. The project also created new collaborations between the participants which had many other benefits. In Latin America, for example, BITNIS offered a way to create a collaborative network of libraries that supported their institutions through a variety of projects, including, for example, activities that led to the creation of a Latin American Network of Disaster Information, another accomplishment of Dr. Lindberg in the years that followed BITNIS [21]. Within NLM, BITNIS strengthened the interest in international computer networks and the Internet to reach a larger audience, create innovative services and enhance collaboration.

Dr. Lindberg believed that the best way to propel the NLM into the future was to reach to users and look at their needs [22]. BITNIS was a great example of his leadership philosophy. Developing BITNIS required a combination of ingenuity, technical skills, the right players, perseverance, and a leadership with vision and an open mind. BITNIS helped the NLM Director bridge the information gap for many people in developing countries and beyond before the Internet revolution. Through BITNIS, Dr. Lindberg supported the nation's efforts to spread good will around the world and brought life-saving biomedical information to many underserved communities at a time when it was most needed.

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When Spider Webs Unite, They Can Tie Up a Lion*: NLM's Work in Information Technology and Health in Africa, 1997–2011

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Abstract: In 1997, Donald A.B. Lindberg M.D., Director, U.S. National Library of Medicine (NLM) agreed to address the request of African malaria researchers for access to the Internet and medical journals as part of the U.S. National Institutes of Health's (NIH) contribution to the Multilateral Initiative on Malaria (MIM). This challenge matched my interests and previous experience in Africa. I joined NLM in 1997 to help establish the MIM Communications Network (MIMCom) in partnership with several NIH components and more than 30 other partners in Africa, the U.S., the United Kingdom (U.K.), and Europe. After a successful launch of MIMCom, NLM worked with African partners to create a series of innovative programs to build capacity in Africa and enhance global access to indigenous African research.

Keywords. Sub-Saharan Africa, National Library of Medicine (U.S.), Malaria, Information Technology, Global Health

1. Background

The challenge that drew me to the U.S. National Library of Medicine (NLM) and to working with its Director, Donald A.B. Lindberg, M.D., came from a meeting of African malaria researchers, funding agencies, and academic and non-governmental organization (NGO) partners in Dakar, Senegal, in January of 1997. African scientists wanted the same tools and support for carrying out research that scientists in the industrialized world enjoyed. African scientists wanted to be able to communicate with colleagues, have access to medical literature, collaborate on proposals, write papers and present their research to the world. They wanted to build capacity through mentoring and competing for grants, create multi-country networks, and send large amounts of data.

Out of this meeting came the Multilateral Initiative on Malaria (MIM) and the critical commitment of Harold Varmus, MD, then Director, U.S. National Institutes of Health (NIH), to assist the African researchers and to put money on the table to do so [1]. Dr. Varmus asked Don Lindberg and NLM to address African researchers' request

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* An Ethiopian adage.
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for Internet access, at the time often practically unusable or nonexistent, and access to medical journals. Don embraced the challenge, and that is where this chapter begins.

In 1997, malaria in Sub Saharan Africa was killing more than one child every minute, based on data available from the Institute for Health Metrics and Evaluation (IHME), Global Burden of Disease (GBD), and the World Health Organization (WHO) [2]. Yet malaria was a minor blip on the radar screen of global health, and most funding for research, control, and treatment in Africa was focused on HIV/AIDS which, of course, had been a scourge in the U.S. as well.

At that time, most major U.S.-based or U.S.-supported funding agencies that would later publicize malaria as a major health issue in Sub Saharan Africa were not yet in existence. The Bill & Melinda Gates Foundation was founded in 2000, The Global Fund to fight AIDS, Tuberculosis, and Malaria was started in 2002, the President's Emergency Plan for AIDS Relief (PEPFAR) was launched in 2003, and the U.S. President's Malaria Initiative was announced in 2005.

In Africa, many research sites had been set up by universities and institutes from the UK and Europe, often, but not always, following old colonial, i.e, top down, or non-governmental organization (NGO) models, i.e, often stand alone and not coordinated with one another or with the health priorities of the African countries where they were based. NLM strove to implement a collegial approach. What follows is a story of listening to the African scientists' concerns and responding to their needs - an unusual modus operandi in 1997.

In the spring of 1997, I took the long escalator out of the Medical Center Metro station in Bethesda, MD, for a meeting at NLM. My family was in the process of relocating to Washington, DC, from Cambridge, Massachusetts. Kent Smith, then NLM Deputy Director, had told my husband Brian Kahin that NLM needed a person with IT, health information, and Africa experience to work on a mandate from the NIH Director. The mandate was to assist malaria researchers in Africa with enhanced Internet connectivity and access to medical literature. Although health IT in Africa today is a crowded (probably overcrowded) field, it was not then, and this specific expertise and on-the-ground experience were not to be found at NLM or NIH. However, as fortune would have it, the mandate from the African scientists mapped precisely with my earlier remit at SatelLife, a small NGO in Cambridge [3].

At SatelLife, I had been part of the team setting up HealthNet. We used a small low-earth orbit satellite, designed and manufactured by Surrey Satellite Technology Ltd in the UK, and simple ground stations on earth, each made up of a computer, "ham" radio, special modem, and send and receive antennae. I had initiated and been director of the HealthNet Information Service which comprised a document delivery service (volunteers using snail mail, diplomatic pouch, or any means possible), a Library Partnership Program between African librarians and librarians in the U.S. and U.K., and HealthNet News. HealthNet News was the first electronic publication for health in Sub Saharan Africa which published weekly and continuously for 20 years (now archived in NLM's History of Medicine Division.) HealthNet, the first telecommunications system for health in Africa, was officially inaugurated in 1991.

During my days at SatelLife, I had met Don who was curious about the small satellite and its mission. Although he saw no possibilities for collaboration with NLM at that time, I never forgot his genuine interest. Fast forward only a few years to what would become the perfect opportunity for me to be part of a much larger collaboration: a need as expressed by African researchers for access to high quality Internet bandwidth and to current medical journals.

This chapter is another testimony to Don's brilliance in bringing together technology with health information, but also his willingness to risk incorporating me, a government outsider with African experience in IT and health information, into the home base at NLM in fulfillment of an NIH directive.

2. Connecting African Malaria Researchers: Multilateral Initiative on Malaria Communications Network (MIMCom)

The Multilateral Initiative on Malaria Communications Network (MIMCom) was one of four main components of the MIM, an international alliance of organizations (governmental, non-governmental, and academic) and individual scientists concerned with malaria research. The other components were a secretariat, a granting agency (with NIH funding for young African researchers administered by a unit of the World Health Organization (WHO), and a reagent center [1]. MIM's aims were to maximize the impact of scientific research on malaria in Africa by promoting capacity building and facilitating global collaboration and coordination. These objectives distinguished MIM from other eradication movements past and present. With marching orders from African scientists, NLM set out to play a role in supporting research objectives and capacity building.

When I think about Don and Africa, I hear his voice and the pithy (often humorous) bits of wisdom he would put forth. Don's guiding phrases were like lanterns along the way and still are. Here are a few from those early days:

- "*What are the people on the ground trying to do that they can't do now?"* Don wanted to help people on the ground do what THEY found difficult, not what WE ("well-intentioned white people" - my words) wanted to do or thought they should do.
- *"Make something work somewhere first."* This was in response to chatter from others about *beginning* with the idea of a big network that MIMCom eventually turned out to be.
- *"First, get two research sites to communicate with one another."* His practicality was wonderful!
- Don believed that we needed to move toward *"where the puck is going to be,"* in the immortal words of the legendary Canadian hockey player Wayne Gretzky.

Under Don's leadership, NLM responded to the mandate from the NIH Director and played a critical part along with the Fogarty International Center, the National Institute for Allergy and Infectious Diseases (NIAID), the Office of the NIH Director, and more than 30 other partners (funding agencies, foundations, and universities in Africa, the US, the UK, and Europe) in setting up MIMCom. MIMCom used a variety of technologies to enhance or introduce Internet connectivity and access to medical literature for malaria research sites in Africa where there was little or no access to either. Eventually comprising 27 research sites in 14 African countries, MIMCom was sustained by the research funders and partners at each site. (Figure 1)

Coincidentally, in the summer of 1997, just as MIM was gaining momentum, NLM, under Don's leadership, took the bold step of making MEDLINE, its premier database, available free to the networked world. Now, anyone with access to the Internet could

Figure 1. MIMCom Sites in 2011

search MED LINE and read abstracts. Getting full text articles was still a challenge. Partner universities with well-stocked medical libraries stepped into the breach. A few years later, full text access became easier for all with the advent of NLM's PubMed Central. The WHO-organized HINARI program also assisted lesser developed countries with access to medical literature.

Don was interested in quality malaria research sites in Africa that had funding partners. This became a guiding principle for MIMCom. To celebrate and incorporate the African scientists' mandate, the project would follow a collegial rather than a colonial or NGO paradigm. That is, we would work with scientists in Africa to find out what it was they were trying, but unable, to accomplish. The focus would be on supporting science rather than gadgetry. The project would not be simply "plug and play" but would involve training, support, and feedback to enable the scientists to carry out their work and achieve their specific scientific objectives.

In the background, I kept my own research question close at hand: How can an IT intervention make a difference in a disease or a health system (malaria morbidity and mortality at a Level II Clinic, for example) in a specific place (Mifumi village, Uganda, for example)? The endpoint should be improved health. If we aren't asking ourselves this question, why are we doing this work? Technology is only a tool.

The challenges were not only in choosing the most suitable and affordable technology for each site but in setting up a system capable of delivering the service each site required while creating synergies for specific research agendas. I recruited Mark Bennett, an English colleague from SatelLife days and an early IT pioneer in Africa, as technical director. Our work plan entailed visits to each site before any technology was considered. Initial surveys documented scientific aims as well as capacity available (or not) to carry out those aims. The team evaluated the availability of local

telecommunications to gain access to browse the web, send email and large data files, and download large documents.

The first questions were always: What is the need - i.e., what do people need to do that they can't do now? Can the technology proposed to address this need be made to work on the ground, given the vicissitudes of electricity? Is the technology solution sustainable – technically and financially? Most important, do the recipients actually view the technology as critical to what they are trying to do, so they might pay money for it and make sure it is integrated into their budgets?

A separate very small aperture terminal (VSAT) satellite system was the answer for two and eventually 10 of the sites. Buying VSAT capacity as a group benefited everyone and underscored the concept of cooperation, even at the technical level [4]. The hope, of course, was that better communication would help prevent wheel reinvention and enhance active collaboration.

We assembled an Advisory Committee of African senior malaria scientists from seven countries across the continent. They offered their expertise on content for a project website, MIMCom Malaria Research Resources, and a weekly newsletter, MIMCom Malaria News (still active as MalariaWorld). They identified their disease priorities, including malaria, HIV/AIDS, TB, and diarrheal disease. Although there was nothing surprising in their list, we believed it critical that priorities were identified by African scientists rather than by funding agencies.

MIMCom was not beholden to any one technology, and was not funded by a single institution, but by a consortium of funders who supported research at each site. Two examples:

- In Ghana at the Noguchi Memorial Institute in Accra and the field site Navrongo Health Research Center in Navrongo: U.S. Naval Medical Research Institute (NMRI)/Naval Medical Research Center (NMRC), NIAID, and the U.S. Agency for International Development (USAID).
- In Kenya, at the Kenyan Medical Research Institute (KEMRI) sites in Nairobi, Kilifi, Kisian, and Kericho and the International Center of Insect Physiology and Ecology (ICIPE) in Mbita, funders included the U.S. Walter Reed Army Institute of Research (WRAIR), the U.S. Centers for Disease Control (CDC), the Wellcome Trust (U.K.), and U.S. National Institute of Allergy and Infectious Diseases/National Institutes of Health (NIAID/NIH).

Given the diversity of partners and funding sources, the administration of MIMCom was difficult to set up and manage and had a number of moving parts. But through the desperate need of the scientists and the education of funders (i.e., connectivity needs to be a line item on research proposals!), this modest experiment became sustainable.

3. Impact of MIMCom on African Researchers

In a January 22, 2001 interview with the author, Dr. Andrew Githeko, Senior Scientist, KEMRI-CDC research site in Kisian, Kenya (one of the first two sites connected on MIMCom) stated:

Now I am functioning as well as anyone in the U.S. and Europe regarding communications. We are a part. We manage projects, some set in Maryland, some set in UK. We forward mail to each other, we plan, and agree and disagree. We run projects in Africa. We are a part. We can discuss plans. It is not one man writing a letter, giving instructions. There is a difference here. . . It's a completely different way of communicating [5].

His view of MIMCom was corroborated in this excerpt from the 2002 report of a review of the overall MIM program:

"We're not so far away, anymore," said one researcher. "We're finally 'here'."

Increasing the connectivity of African scientists, both with each other and with scientists in the rest of the world is a role that MIM has played well. Electronic access to journals and a new ability to communicate easily with other scientists, together with MIM-provided opportunities for face-to-face meetings at workshops and conferences, has greatly facilitated Africa capacity development.

High-speed Internet connection to the WWW and e-mail has created an almost entirely new set of opportunities for the scientists located in the MIMCom centers. Many of the sites feel that they would no longer be able to function without this facility and regard the enhancement of connectivity as a significant step toward reducing the inequities of research advantages in the North compared to the South.

The creation of MIMCom has provided isolated scientists with tools that bring the whole world closer. Reliable communication with collaborators and vastly improved access to the scientific literature have both increased the reach of African scientists and facilitated their participation in the broader scientific world, especially by improving their ability to publish in world-class journals, a key part of being a mainstream scientist [6].

MIMCom facilitated malaria research in: epidemiology; antimalarial drug resistance; pathogenesis and immunology; entomology and vector studies; natural products and drug development; and health systems and social sciences. A survey of researchers at MIMCom sites conducted from August 2002-February 2003 showed MIMCom was making a significant difference in professional performance among collaborations with colleagues, short courses taken, proposals written and funded, papers published, and clinical trials. Connectivity counteracted isolation and improved self-esteem [7].

And it all started with helping two sites decide what they needed to do and then supporting them in communication with one another. Seven years later, connectivity at the MIMCom sites across the continent was sustainable, and the sites were on their own to choose how they wanted to develop their telecom futures [8].

4. MIMCom as a Spark for Additional NLM Capacity-Building in Africa

Don liked the strategy of linking new initiatives to existing successful programs. The three initiatives that follow - with African medical librarians, journal editors, and medical students - were possible due to the success of MIMCom. They were patterned on my earlier work at SatelLife and coordinated with extant core programs at NLM. All focused on specific need and on local sustainability, ownership, and autonomy.

4.1. NLM African Associate Fellows and the Network of African Medical Librarians

Don admired the NLM Associate Fellowship program, a long-standing year-long post-masters training program for librarians. This program was primarily domestic, but Don approved adding an international slot. In 2001, he supported a proposal to focus the international slot on Africa, strongly advocating that African Associate Fellows undergo the same curriculum with U.S. Fellows on-site at NLM.

As part of my earlier work at SatelLife, I had gotten to know a number of medical librarians across Africa. In the countries where SatelLife had nodes, the librarians often ran the ground stations, mastering the technology to pull down messages and HealthNet News from the satellite and distributing them in hard copy to physicians and scientists.

Nancy Kamau, a librarian from the Kenya Medical Research Institute (KEMRI) whom I had known since 1990, became the first Associate Fellow from Africa. While at NLM, she was able to assist KEMRI's *African Journal of Health Sciences* in submitting XML tagged data to NLM for inclusion in MEDLINE/PubMed, while helping NLM develop guidance to assist other journals in developing countries to do the same. Don was very pleased with this outcome and Nancy's role in bringing it about.

Nancy's view of her experience as a Fellow echoes sentiments of researchers connected by MIMCom: "When I was at home in my library, I felt like I am all alone, but when I came here [to NLM] I knew that there are so many people out there who can assist me if I needed something. There is so much I can do . . . ."

All told, six medical librarians from the African continent have participated in the NLM Associate Fellows Program. These librarians and other NLM partner librarians in Africa came from academic institutions in Kenya, Mali, Morocco, Mozambique, Nigeria, Uganda, Zambia, and Zimbabwe.

In 2009, NLM supported the formation of the Network of African Medical Librarians (NAML), an independent consortium with a secretariat in the Office of the Vice Chancellor at Kenyatta University in Kenya. Organized as a network, the librarians maximized their strength as a group, sharing their expertise across the continent. They have assumed leadership positions in the Association for Health Information and Libraries in Africa (AHILA) as well as its country chapters. The Network's vision is to strengthen health sciences education, research, and outreach for better health outcomes in Africa. Their mission is to expand the frontiers of health information through outreach to and training of African librarians, the academic community, health care professionals, and health policy makers. The Network has been active in improving electronic access to research and health care information in Africa. (Figure 3)

Illustration by Ronnie Ogwang

Figure 2. Artwork commissioned for the African Digital Health Library project

4.2. Strengthening African Medical Journals: African Journal Partnership Program (AJPP)

From time to time, African medical journal editors would give me copies of their journals to take back to NLM. They were keen to be indexed in MEDLINE. Don wanted to strengthen African medical journals, so they could be part of the main game (MEDLINE), as opposed to living in a separate regional database that few would see. He believed everyone would benefit from access to African research.

As in other developing regions, African journals often lack the necessary resources to carry out peer review and publish regularly. To address these needs, the African Journal Partnership Program (AJPP) was created in 2004 as a health and medical journal capacity building program in Africa. The initial AJPP collaboration comprised NLM, which provided major funding, the Fogarty International Center, the National Institute

of Environmental Health Sciences, and nine journals from Africa, the US, and the UK. The Council of Scientific Editors provided the secretariat for the partnership [9].

The mission of AJPP was to promote publication excellence in African health and medical journals and allow for wider dissemination of African research results. The founding meeting was held at the British Medical Association and hosted by the British Medical Journal (BMJ) in London.

The AJPP created partnerships between interested African health and medical journals and leading journals published in the United States and the United Kingdom. The premise was that learning would be two-way with this partnership opportunity. The goal of the program was to strengthen the African journals, so that they could be accepted into MEDLINE and make African research results available to the world. Valuable research carried out in endemic countries is not often available to a wider international audience.

The AJPP's objectives were to facilitate the collaboration of African journal editors with counterparts at international journals; improve the technical production capability of African journals; support training of writers, reviewers, and journalists in the field; encourage the editors in planning for succession and sustainability; and help journals earn acceptance for indexing into MEDLINE and other major databases. The partnership began with four African journals; six more were added later. As of April 2021, five participating journals from Ethiopia, Ghana, Malawi, Mali, and Uganda had been accepted into MEDLINE.

In an August 5, 2013 interview, James Tumwine, Editor in Chief of African Health Sciences and Professor of Paediatrics and Child Health, Makerere University College of Health Sciences, Kampala, Uganda told the author:

> The AJPP has been a catalyst and has enabled us to, through small funds, do a lot of work. Our journal has grown. We have been indexed on MEDLINE, and recently we were indexed on ISI and have an impact factor. To us, that means quite a lot. It means we are equals, among equals.
>
> When we started the journal, the impetus was to have an African journal publishing African material. We were finding it extremely difficult to have our scientific material published in western journals for various reasons.
>
> I am really so glad that we are now able to publish like other journals. It has been quite difficult, but AJPP has done a lot to help us along the way. …. AJPP gives us a lot of visibility, and also credibility, and, of course, citations. So, it is being visible but also being sustainable that has been, to me, the biggest achievement. …. Our initial partnership was with the British Medical Journal, and we learned enormously from the BMJ. They are an extremely large journal with a very huge building. We are a very small journal in a small building. But we really appreciated their ideas and their suggestions and used them to maximize time and human resources. … We have learned to use small bureaucracy to do big things. ….
>
> I am married to free access. If we can publish material and make it available, freely available, then we are training our students and our staff and keeping them up to date. They will be high class scientists and health workers. That's what motivates me.

4.3. MedlinePlus African Tutorials Developing a Culture of Research and Community Involvement: African Medical Students

One afternoon in a noisy hallway as classes were changing at Makerere's School of Medicine in Kampala, Uganda, I showed eager students NLM's popular MedlinePlus website. They were especially engaged by the interactive tutorials. Why not create tutorials for diseases in Africa? Of course, malaria was the obvious first choice, and the ingredients to move forward were there.

Don was a strong believer in training, mentoring, and encouraging student work and ideas throughout his career, and his support was critical. Prior to joining NLM, I had enjoyed meeting medical students while in Uganda and had strong working relationships with their elders: the Dean of Makerere University's School of Medicine as well as the Head of the Albert Cook Medical Library. The idea could grow from here.

We brought together the students and their faculty advisors with Ugandan artists, actors, and translators to create tutorials on malaria and diarrhea. When they were ready to go online and become part of the MedlinePlus database, NLM's MedlinePlus team back in Bethesda was ready to collaborate.

Early versions of these tutorials were field-tested by the students as part of their medical school program called COBES (Community-Based Education and Service) during which students engage in field work at the village level. For several weeks during each year of their medical training, students go back to the same village for two-way learning. After a favorable response and learning what worked and what didn't during the field-testing, the students made laminated booklets and posters, and a local producer incorporated audio versions with actors speaking in local languages. The students were now ready to use the "information intervention" for rural communities to be used as part of COBES. But we needed just the right platform for implementation.

Fortunately, African colleagues had taken me out to a village called Mifumi in Eastern Uganda. Mifumi had a good health center with medicines, electricity, and a small staff of health workers and nurses, overseen by a Nurse Sister. The students, their medical skills, and their "information intervention" were warmly welcomed. Back at the School of Medicine, we were able incorporate this village officially into the COBES program. During their first visit to Mifumi, the students created a survey to ascertain a baseline of malaria knowledge in the village. The results of this survey informed the final content of the tutorials.

The booklets and posters were distributed throughout the COBES program. The students learned about working at the village level and the local beliefs people held about their health. Some students had never lived in a village and might find their passion for care at that level. Others would go on to work on the wards of a hospital and never see much of village health care again. The Dean believed that exposure to health issues at the village level was imperative to medical training.

In addition to providing a learning experience for the students at all levels, this initiative also produced Don's favorite example of how local beliefs can affect health: in various regions of Africa, there exists the belief that mangos cause malaria.

Figure 3. Page from the MedlinePlus African Tutorial on Malaria

From an interview by the author in 2007 with three medical student project leaders – Nixon Niyonzima, Nelson Igaba, and William Lubega– at Mulago Hospital, Kampala, Uganda:

> Niyonzima: *The original draft [of the tutorial] was tailored by doctors and by medical students not culturally adapted at that time. What was put in the draft was what was in the books, not community beliefs. ....When it is the mango season, it is the rainy season, so you can really connect the two. We have malaria highest during the rainy season, we have mosquitoes highest during that time, and people attribute malaria to mangoes and rainfall. And then, of course, there are people who tell you that malaria is caused by mosquitoes, and this is what we expected people to know. But then there are those who will tell you maybe it is God; you have done something wrong, and God is punishing you.*

> Igaba: *If you go there and tell someone to put water in the fridge and he has never seen a fridge, you'd better tell the person, you keep water in a pot. Because they have seen pots. You just teach them how to keep the pot clean. We thought of redrafting the tool, which has helped us fit the culture of the people we talk to, and they understand, because we are talking to them through what they are used to.*

> Lubega: *We carried out a baseline survey on malaria to find out how much the people knew about malaria, their attitudes on malaria, their practices. We go into the community, we collect what their beliefs are, and we look at the main information from the medical profession. Then we integrate the two in a multidisciplinary approach to reach out to the people within the communities. ....*

> *We are very excited about the posters because people saw things in the posters that they could relate to in their own communities. For example, the mangoes. The [health workers] have been telling people about malaria, but they didn't have anything tangible that the patients could walk in, see, and easily relate to. People remember the visuals and learn to associate the vector with the disease, which was very important for us.*

> Niyonzima: *a part of the NLM Tutorials for Africa project elevates someone from a position of powerlessness and inability to one of endless possibilities. That is, knowledge is power. And when you get the knowledge, you are able to create a difference in somebody's thinking and somebody's actions. We have been able to reach out to several communities to educate them, empower them, and give them the ability to change their livelihood, to change their situations. People might feel powerless because they think that malaria is a punishment from God. Now they can do something about it because they are empowered, they have the knowledge. We think the goal is to make a difference in society.*

In a later collaboration with Ugandan health informatics experts and under the guidance of the Nurse Sister, students conducted an observational study in actual use of bednets to prevent malaria, employing a digital pen application (in partnership with NLM technical staff) for collecting data [10]. This project concluded with a community meeting in Mifumi village in which the students presented their research findings to the village. More than 150 people came and stayed for two hours [11].

This work in Mifumi village inspired expansion into other tutorials designed to help both health professionals and communities deal with local health problems, including mental health in war-torn Northern Uganda, tuberculosis, diarrhea, and Burkitt's Lymphoma, the latter in collaboration with the National Cancer Institute.

5. Epilogue

What started as an access and connectivity effort in collaboration with NIH spawned related capacity building programs with medical librarians, medical journal editors, and medical students – in academia and in the village – all developed in the rich soil of NLM. Don was supportive of each one. He knew I wanted to help our colleagues in Africa - and he did, too. NLM was the perfect stage for giving voice to the women and men of African science and medicine. We demonstrated a collegial approach which tried in every way to eschew old colonial paradigms.

Today, the playing field is not exactly level, but many African researchers, clinicians, health workers, not to mention academics and students, have some tools that enable them to carry out much of the quotidian business of science and medicine. They can communicate with one another and collaborators all over the world; they can network with colleagues, learn of deadlines for grant proposals and submit applications, and write papers for publication. Their contributions are critical. The next chapter will be written by those who use the tools we have shared to navigate the noisy information environment and create new solutions unique to Africa.

I had the privilege of being an "Africa advocate," as my WHO colleague put it when she heard I had been recruited to NLM. I loved working there and was proud to represent NLM on the African continent. NLM was truly the jewel in the crown of NIH and the best face the U.S. government could possibly have in Africa.

My gratitude to our late leader Donald A.B. Lindberg M.D., Director, U.S. National Library of Medicine, who was open to new possibilities, encouraged imagination, and gave me a long leash!

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Native Voices Exhibition: Stories of Health, Wellness, and Illness from American Indians, Alaska Natives, and Native Hawaiians

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Abstract. The U.S. National Library of Medicine (NLM) exhibition known as Native Voices reflected Donald A.B. Lindberg M.D.'s keen and long-held desire to help improve public understanding of Native American health challenges and honor the culture, tradition, and healing ways of Native Peoples. A centerpiece of the exhibition was a large set of video interviews that Dr. Lindberg conducted with Native health and community leaders. Dr. Lindberg and his team engaged Native advisors in the exhibition development; sought Native input through Listening Circles, Tribal Consultations; and site visits, and made the video interviews accessible via interactive kiosks and iPads. For its time, this was state-of-the-art exhibition technology. The exhibition also included Native artifacts and art works to complement the videos, including a scale model of the iconic Hokule'a Native Hawaiian voyaging canoe, and a full-size Lummi Indian Healing Totem Pole. The totem journeyed across the U.S. prior to its installation next to the NLM herbal garden in Bethesda, MD. A traveling version of the exhibition visited more than 130 venues in 40 States across the U.S. The interview clips and other content are accessible on the exhibition website, and the full-length interviews are retained in the NLM permanent video collection.

Keywords. U.S. National Library of Medicine, Donald A.B. Lindberg, M.D., Native People, Native American, American Indian, Alaska Native, Native Hawaiian, Indigenous Knowledge, Native Healing, Health, Wellness, Illness, Video Interview, Hokule'a, Totem Pole.

1. Introduction: Dr. Lindberg's Vision Becomes Reality

Native Voices was a multi-media interactive exhibition on Native People's Concepts of Health and Illness that officially opened at the U.S. National Library of Medicine (NLM) on October 5, 2011. It featured innovative video interviews with more than 80 Native American health and community leaders, resulting in over 250 video clips, the largest such collection of Native American videos known to exist. The video content was presented on interactive displays iPads, and on the exhibition website [1].

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The exhibition was called "Native Voices" to emphasize the importance of sharing Native People's views of health, wellness, and illness in their own words and voices, not filtered through non-Native perceptions. For purposes of this exhibition, NLM defined both the terms Native Peoples and Native Americans to include American Indians, Alaska Natives, and Native Hawaiians.

The physical exhibition was on display in NLM's main exhibition space (known as the Rotunda), from 2011 to 2015. The exhibition included displays of Native artifacts and art work, and an interactive Native history timeline, to complement the videos.

On the Rotunda floor, the videos and related art works and photo displays were organized around four themes with illustrative topics:

- Medicine Ways - Medicine Wheel, beliefs, ceremonies, prayer, Creator, higher power, elders/healers, ideas, language, plant medicine.
- Healing Communities - Kalaupapa settlement, education, boarding schools, games and sports, surfing, powwow, reservation life, role models, tribal ties.
- Native Heritage - Native veterans, Code Talkers, family, identity, art, nature, land, plants, water.
- Many Paths - Intersection of Western and traditional healing, Native doctors and health centers, diseases/disorders, ideas, urban Indians.

The four thematic kiosks in the Rotunda featured video clips representative of all of the interviewees, accessible on large digital touchscreen displays, highly searchable with high-quality video and audio playback. An additional offering on the exhibition floor was what Dr. Donald A.B. Lindberg M.D. coined, "the coffee bar." While beverages are not allowed in the Library, the phrase referred to a high-top table with bar stools where visitors could sit and explore full versions of several key interviews. The latter represented diverse Native populations and were provided via iPads loaded with an early version of the Native Voices mobile application.

Dr. Lindberg's vision to create a high-resolution video archive of the interviews enabled the development and production of increasingly popular mobile applications. The traveling version of the exhibition was designed around iPads that featured the interviews and enhanced content. The traveling versions visited more than 135 locations in the U.S. from 2013 to early 2020. The website version was launched in 2011 and remains accessible [1].

Native Voices included extensive outreach and consultation with Native Americans prior to, during, and following development of the exhibition. The exhibition itself was a form for public education and outreach, intended to enhance public understanding of Native health and health practices as well as challenges.

The exhibition was designed to reach varied audiences, including the general public, Native leaders, communities, health providers and healers, educators and students. Where possible, the exhibition used state-of-the-art information and audiovisual technology that facilitated interactive information access to the interview video clips, and related introductory and event videos.

Dr. Lindberg, then the NLM Director, summarized his Native Voices Vision in his introductory video to the exhibition:

> *Welcome to the National Library of Medicine, the largest medical library in the world, and to "Native Voices: Native American Concepts of Health and Illness."*

Photo 1. Opening of Native Voices at NLM, with Ribbon Cutting by NLM Director Lindberg with Cynthia Lindquist, Katherine Gottlieb, Yvette Roubideaux, and other leaders, 2011.

You will hear individuals speak to us about their own ideas of health and illness, how these happen, how death fits in too. They will speak of traditional healing ways, modern treatments, their ideas about loyalty and military service.

The NLM chose to present this exhibition because of our growing admiration for many of the ideas and practices of American Indians, Alaska Natives, and Native Hawaiians.

These people do have different mental models and attitudes, if you like, about life but they also share important beliefs.

First, Native people seem to us to share a common view that each person has a responsibility for his or her proper behavior and health. This includes such matters as diet, exercise, traditional or Western treatment, hospice care.

Second, you'll gain a sense of how these Native people place the tribe, the group, the village at the center of their beliefs about health and happiness. The rebirth of voyaging and the canoes of Hawaii seek to rebuild the peoples' pride in their group and its seagoing history. You'll see Choctaw boys and girls taking charge of their own health through traditional sport.

Third, there's a common high regard for Nature, the climate, the plants, and animals, and the land itself. It's a complex topic that blends physical reality with spiritual reality.

Fourth, when you listen to the interviews, you will surely hear a reverence for traditions for tribal elders and for a supreme being.

Fifth, the Native groups all share a history that is lamentably full of rough, unfair treatment as our modern American and Western European industrial

civilization enveloped Native lands, abolishing ancient sources of pride. Our timeline shows the history of groups. Interviews of individuals suggest that loss of pride and purpose can be serious obstacles to healthy living and to recovery from illness.

Our exhibition is also about young Native people today and how they incorporate all these experiences in their own ways to make their lives happy and healthy.

Throughout all these discussions is the art of Native people. The art objects represent the ideas of the people often magnificently.

Come back to NLM anytime, read about any of the things you see today. For now, have a fun and enjoyable visit.

2. Origin of the Exhibition

Dr. Lindberg's early interest in Native Americans began with his summer externship at the Good Samaritan Hospital in Phoenix, AZ, while still a student at Columbia University College of Physicians and Surgeons. From his Phoenix base, he visited several Indian Health Service facilities in the region. He never forgot these experiences, which generated a latent desire to eventually do something to help the Native American community. This desire was reinforced by his continually growing awareness of health disparities in Indian Country.

Much later, that opportunity emerged in part from Tribal Connections, an NLM outreach project that ran from 1997-2002. Tribal Connections helped connect isolated Indian tribes in the Pacific Northwest to the early Internet and online health information. [2-6]. An Alaskan Native advisor to Tribal Connections, Theodore A. Mala, M.D., M.P.H., continued his association with NLM and in 2003 discussed innovative means by which NLM could expand its outreach programs with Native Americans.

Dr. Mala initially proposed to co-author Elliot R. Siegel, Ph.D., the convening of a series of Listening Circles in which NLM's director (Dr. Lindberg) would personally visit with Tribal Chiefs and Elders on American Indian reservations, and with Native communities in Alaska and Hawaii. The visits would seek to gain a better understanding of Native People and their health information needs, leading to new efforts by NLM to enable better access to health information resources from NLM. Dr. Lindberg quickly embraced the idea, and a series of Listening Circles was convened in 2003-2004 in which Dr. Lindberg and NLM staff actively participated.

What Dr. Lindberg heard was not only information about Native Peoples at individual and community levels. He also heard a Native desire to tell their own stories of health, wellness, and illness in their own words to a non-Native audience that was largely unaware of the existence of Native Peoples and their traditional medicine concepts. From this emerged Dr. Lindberg's initial vision for an exhibition on "Native Peoples' Concepts of Health and Illness," later informally amended to include "wellness," as many interviewees talked about health, wellness, and illness. It would be told in first person stories by Native healers, and elders, tribal and community leaders, and Native youth, recorded in high quality video interviews for the exhibition, and would be preserved in perpetuity. This was the basis for the "Native Voices" short title.

Dr. Lindberg's early vision was informed and reinforced by extraordinary Native advisors who worked assiduously to better public understanding and, literally, opened

the doors to the Native healers and leaders whose stories would be presented in the exhibition.

The exhibition concept was energized, refined, and greatly enhanced through a series of Tribal Consultations that comprised many local face-to-face meetings that also offered authentic and sometimes physically challenging settings and opportunities to conduct video interviews with Native participants. These became the core content of the exhibition and are a testament to the trust that was placed in Dr. Lindberg. Interviewees represented a cross section of Native Americans - by age, sex, role, and physical location, elders and youth, chiefs and healers, rural and urban.

3. Native Advisors and NLM Team

The original vision of Native Voices was Dr. Lindberg's with the help and support of diverse Native leaders and NLM staff. Key Native collaborators included: Dr. Ted Mala (Alaska Native/Inupiat Eskimo); Cynthia Lindquist, PhD (Spirit Lake Dakota); Marjorie K. Leimomi M. Mau, M.D., M.S. (Native Hawaiian); Katherine Gottlieb, MBA, DPS (Alaska Native/Sugpiaq/Filipino); and Aunty Agnes Cope (Native Hawaiian). These and other collaborators provided invaluable advice and connections to establish the level of trust needed for NLM to effectively partner with Native communities, and for Dr. Lindberg to conduct the interviews. For additional Native collaborators, see the Native Voices website credits page [7].

Dr. Lindberg conducted more than 100 video interviews as part of the Native Voices project. He was supported in that role by NLM's Audiovisual Program Development Branch (APDB), headed by Anne Altemus (then acting chief, APDB, Lister Hill Center for Biomedical Communications - LHNCBC), project manager and production supervisor, and John Harrington, video producer and director, from Madison Films Inc., working for the APDB. See section 6 for further discussion of the Native Voices videography and production.

Native Voices was a remarkable trans-NLM project, with contributions from nearly all of NLM divisions. The core NLM team members included the following, who participated in the regular planning meetings. The lead coordination was provided by Drs. Elliot Siegel and Fred Wood of the Office of Health Information Programs Development (OHIPD). An exhibition planning team met monthly, chaired by Dr. Lindberg, and included, in addition to OHIPD and APDB: Gale Dutcher, Specialized Information Services Division; Kathy Cravedi, Office of Communications and Public Liaison; Robert A. Logan, Ph.D., Office of the Director; Jeffrey Reznick, Ph.D., History of Medicine Division, and others from across the library as needed. Ivor D'Souza and his staff from the Office of Computer and Communication Systems (OCCS) assisted with the Rotunda information technology implementation. Two Native Americans provided important staff assistance - John Scott, M.A., Consultant (Alaska Native/Tlingit), and Dylan Rain Tree, MPA, JD (Mono/Choinumni/Pomo Indian from California). Rain Tree initially was a WINS Intern (Washington Internship for Native Students) and later became a member of the OHIPD staff. Margaret Hutto served as lead field coordinator for the NLM phase of the traveling exhibit. Patricia Carson, special assistant to Dr. Lindberg, provided overall schedule planning and coordination for Dr. Lindberg's heavy involvement with Native Voices. Mary Lindberg accompanied Dr. Lindberg on several Native Voices visits and provided valuable observations and insights along the way.

In sum, Native Voices was an amazing collaborative effort, with many contributors, and for which Dr. Lindberg provided overall direction, visionary ideas, and hands-on involvement in key aspects. He was a champion of the innovative use of state-of-the art information and audiovisual technology wherever possible.

4. Listening Circles with Site Visits

NLM held three Listening Circles in 2003-2004. Each involved an in-person dialogue between Native leaders and Dr. Lindberg with NLM staff taking notes and chiming in where appropriate. The focus was open ended on any health-related topics and issues of concern to Native participants, and ideas on how NLM resources could help. The exhibition had not been conceived at the time of the Listening Circles, so the discussion was not within an exhibition frame of reference, although much of the discussion ended up being relevant. Video interviews were not yet envisioned, and thus were not conducted at the Listening Circles. The locations for the Listening Circles were selected in part to reach out to each of the three major Native groups - American Indians, Alaska Natives, and Native Hawaiians, and where NLM already had established Native contacts through prior outreach projects. See Appendix 1 for further information on the Listening Circles.

5. Tribal Consultations with Interviews and Site Visits

NLM held six Tribal Consultations in 2006-2011. Dr. Lindberg and NLM staff met with Native leaders in group session and/or individually, with video interviews conducted sometimes as an adjunct to a meeting but always as an important activity. The Tribal Consultation agendas were focused on possible exhibition topics and exhibit material. And the video interviews included questions and topics directly relevant to the exhibition. Each consultation included site visits to venues of significance to the local Native peoples.

Dr. Lindberg participated in all the Listening Circles and Tribal Consultations, and through these many discussions, site visits, and the video interviews, his concept of the exhibition was further developed and refined. See Appendix 2 for further details on Tribal Consultations.

6. Interview Videography and Production

From the very early phases of planning the exhibition, Dr. Lindberg was steadfast in his commitment to the highest quality production video and audio. He not only recognized the importance of creating an archival video database that would be both preserved and available for the future, he also wanted to honor the brave and generous people who were willing to be interviewed, and tell their stories. Producing the best possible version of the interviews honored the interviewees.

Following the Listening Circles and in the early phase of Tribal Consultations, Dr. Lindberg realized that the use of videography to record his interviews with Native healers and leaders could become the center point and defining contribution for the exhibition.

Dr. Lindberg engaged, guided, and learned from the interviewing process, and he kept pushing for the highest quality video product. In addition, he stayed centrally involved in both pre-production planning, the post-production and editing process, and efforts to organize the videos for public access.

After a period of trial and error, Dr. Lindberg concluded that NLM's own Audiovisual Program Development Branch (APDB) needed to head the production effort (knowing that this group excelled in the application of emerging video acquisition, production, and storage formats) in order to assure the highest quality video product. Dr. Lindberg appointed Anne Altemus, then acting chief, APDB, as the lead project manager and production supervisor, and John Harrington, as senior producer, who was and is President of Madison Films Inc. Dr. Lindberg was closely involved, and in addition to conducting all the interviews, he collaborated on technical quality assurance and the ultimate presentation of the video final products in the NLM Rotunda displays including touch screen kiosks and iPads, and the use of iPads as part of the traveling versions.

6.1. Video Interviews as Centerpiece

Following the 2006 Alaska Native consultation, Dr. Lindberg determined that Native interviews, with the Native storyteller as the focal point, would be the primary device used to tell the exhibition's many stories. From October 2006 onward, all videotaping featured Dr. Lindberg as the interviewer, using Anne Altemus as production supervisor and John Harrington as producer. Initially, the film crew was locally provided. From June 2008 onward, an NLM arranged video crew was deployed for quality assurance purposes.

The added benefit of a dedicated NLM video production crew was the cultural sensitivity necessary for the crew to gain the respect and trust of the Native communities that were recorded. Frequently, advanced production communication was required to schedule and scout locations, set-up, and other logistical requirements, which were as varied as the landscapes that were visited. All of the venues were unique, but production quality had to remain consistent.

6.1.1. Ambassadors for NLM

Along the way, the video production team became ambassadors for the NLM and the exhibition with the full support of Dr. Lindberg. One of the Hawaii visits was the longest, with travel throughout the islands that required cars and planes, and a lot of muscle to pack, carry, set-up and break down lights, cameras, endless cables, and power strips. Advance visits to locations meant the video crew was the first flight of NLM staff who met with communities and individuals. Cultural respect was critical to success at every shoot. Along the way, the production crew gained Dr. Lindberg's trust and respect, and the feeling was mutual. Over the years, through planning and production, post-production and traveling, Dr. Lindberg challenged the technical process, and fully supported the exploration and implementation of advanced video formats and techniques. Planning and logistical challenges were constant.

Many of the interviews were raw and emotional, sometimes challenging. There were quite a few interviews that had a significant impact on Dr. Lindberg, and the crew. The stories that emerged were tragic, compelling, inspiring, and hopeful. In the end, the resilience of Native People emerged over time. And hospitality was always generous. Dr. Lindberg was always present in the moment, immersed in the experience, whether it was

a pow wow, a ceremonial performance, a shared meal, or quiet moment. Sitting on a bench on the porch of the Queen Emma Palace in Honolulu, waiting for an interviewee to arrive and after an earlier, very difficult interview, he reflected on how he might have handled the interview better. By example, he inspired all on the videography team.

6.1.2. Videography + Photography

Native Voices provided Dr. Lindberg an opportunity to combine his interest in top quality photography and videography with his desire to learn much more about Native health and healing concepts from the Native Americans themselves.

One example occurred on a 2013 trip to open the traveling exhibit at the Cankdeska Cikana Community College, a public tribal land-grant community college in Fort Totten, North Dakota, on the Spirit Lake Reservation. NLM staff and crew were invited to an early morning off road tour of a 'buffalo' ranch. Dr. Lindberg sat in the front of the rancher's pickup truck, riding "shotgun" (next to a shotgun) for the tour. He talked to our host with ease, about ranch life, the sacredness of the 'totanka' in the culture, and the beauty of the land. In his hand for the whole ride was one of his cameras, capturing as many moments as he could. Every journey made for the exhibition found him with a camera in his hand.

Dr. Lindberg's passion for photography explained his understanding and encouragement when NLM's crew was shooting in 4K resolution for the first time in Alaska in August of 2013, with a prototype 4K video camera on loan from Sony. On the last day, when production ended fairly early, the crew proposed driving toward Mount Denali to shoot scenic b-roll. Dr. Lindberg's response: "Chase the clouds - and get some good stuff!"

That particular trip, like so many, was a test of strength and logistics. Dr. Lindberg enjoyed hearing about the journey, including hiking up the trail to see a glacier with a heavy camera and lens. On the extraordinary trip for a privileged stay in Kalaupapa on the island of Molokai, the small plane carrying Dr. Lindberg, the production crew, and NLM contingent, could not accommodate the weight and size of all of the production equipment. A separate charter was required to fly the equipment to the settlement. On so many occasions like this one, Dr. Lindberg knew the value of doing whatever it took to "get it right." His support for the overall production quality was extraordinary.

6.1.3. Filming in the Field

Most of the video interviews were conducted at field locations (with a few at the NLM video studio in Bethesda, MD). The field video work was challenging and required background research to identify potential site visits and interviewees, and collaboration with Native organizations to obtain support for participation. NLM's key Native advisors were very helpful in facilitating and arranging interviews.

Preparing for interviews helped bring focus to the overall exhibition development. Dr. Lindberg and the NLM staff prepared lists of focus questions to share with prospective interviewees. The list went through several iterations. Dr. Lindberg used his discretion to customize the topics and questions depending on the interviewee, with the result that most interviews flowed well and covered the key subjects. Interviews typically lasted about 20 to 40 minutes in raw video footage. All videos were recorded with High-Definition digital video cameras.

And yet, in spite of the research and preparation, the best content featured stories that emerged from the conversation on camera, after the key questions were asked and a

topic of mutual interest was shared. For example, Dr. Lindberg's interest in the Mohawk Iron workers sparked a wonderful conversation with Thomas Cook, a Wolf Clan Mohawk Indian who spent five years as a high-elevation iron worker in New York working on the World Trade Center. There were many moments like this one, which demonstrated Dr. Lindberg's genuine interest in people, their stories, and common experience.

In addition to the video interviews, the video team shot "B-Roll" footage where possible, in order to have Native cultural, historical, geographical, health, and community imagery available. The B Roll enabled the preparation of several introductory and special event videos that include interview segments in context.

Several of the B Roll and other videos are accessible on the Native Voices website, including:

- Introductory video by Dr. Lindberg;
- Exhibition overview video;
- Exhibition opening ceremony video;
- Exhibition thematic introductory videos (total of 5 videos);
- Totem pole journey videos (total of 21 videos); and
- Traveling exhibition opening ceremony videos (total of 4 videos).

6.2. Video Post-Production

Another significant challenge arose in post-production - transforming the raw video interview footage into 200+ video clips typically 25 to 45 seconds long, to optimize viewer attentiveness. The editing process was preceded by a project to identify and organize key terms, themes, and topics/subtopics with which to categorize and organize the video clips.

The combination of identifying, editing, and organizing the video clips was time intensive, but was important to Dr. Lindberg and the video production team as the clips were a core element of the exhibition. The final top level organizing themes were determined by the most common concepts that emerged from the interview transcripts.

Again, to accomplish this, Dr. Lindberg turned to specialists in the Lister Hill National Center for Biomedical Communications (LHNCBC). Thomas Rindflesch, Ph.D., Cognitive Science Branch, had a specialty in thematic indexing. Based on interview transcripts of all of the exhibition interviews, Dr. Rindflesch identified thematic clusters of words and concepts that emerged from the interviews. These were themes that flowed through all of the Native tribes and communities represented in the exhibition, and they formed the thematic flow of the content in both the physical and digital elements of the exhibit. The latter approach was essential to Dr. Lindberg. He wanted the themes of the exhibition to be authentic, based on the experiences and perspective of Native people.

6.3. The Interviews: Five Common Themes

The five common themes that emerged from the interviews were: Community; Healing; Individual; Nature; and Tradition. In sum, 88 interviews were divided into a total of 288 video clips organized around these five themes. The video clips also were cross-indexed by interviewee name, and geographic region (e.g., Southwest, Southeast, Alaska, Hawaii). In turn, the video clips could be searched by theme, name, and geographic area.

The video clips are presented on the Native Voices website in the "Interviews" section [8]. The clips also were displayed on the touch screen kiosks in the Rotunda exhibition and were accessible via iPads on coffee tables in the Rotunda, and on stands to accompany the traveling versions of the exhibition.

The distribution of video clips among the themes, and topics within each theme, is shown in Appendix 3. Appendix 4 is an extension of Appendix 3. Appendix 4 contains a representative selection of video clip transcripts, which illustrate the breadth and richness of the video clip content.

Dr. Lindberg was very proud of the multiple display options for the video clips - what he perceived as the crown jewels among the several wonders of Native Voices.

7. Native Art and Artifacts

Dr. Lindberg was on the lookout for distinctive Native art works and objects that would be keynotes of the physical exhibition. He initiated visits and requested searches of Native and other museums for items to display in the Rotunda. These included: a vintage heavy redwood Hawaiian surfboard; Holua sand sled; stone mortar and pestle; Duke Kahanamoku's 1920 Olympics swimming gold medal (all from the Bernice Pauahi Bishop Museum); a Navajo Code Talker style World War II radio from the National Electronics Museum; and cultural objects such as "Spiritual Beauty." Others included: Duwayne M. Chee Jr., Navajo, 2003, ceramic, from the Eiteljorg Museum of American Indian and Western Art. The Eiteljorg Museum additionally loaned historic artifacts including a Zuni medicine bowl (circa 1962), Lakota pipe (c 1890) and pipe bag (c 1900), Cheyenne and Kiowa rattles (c 1940), and a Lakota drum (c 1960).

Hundreds of additional photos, maps, and sketches were included in the interactive timeline of Native history, which was developed by the exhibition team at Dr. Lindberg's request. The goal was to provide an historical context for the exhibition. The timeline was included in both the Rotunda and website versions of Native Voices. The timeline covered major historical eras, from the era of First Nations, prior to 1492, to the most recent era of Renewing Native Ways. The timeline entries were organized around the topics of Epidemics, Federal-Tribal Relations, Land and Water, Healing Ways, and Native Rights as applicable to each era.

See Appendix 5 for additional examples of art and artifacts included in Native Voices. Also at Dr. Lindberg's request, NLM included a book shelf and a Native news display, to complement the Rotunda exhibition. For a small sampling of the books on the bookshelf see [9-21, 23-25, 29]. Dr. Lindberg also was a dedicated reader of books on Native American history, healing, culture, and art.

8. Hokule'a Voyaging Canoe

Dr. Lindberg wanted something big and symbolic for the exhibition, that would convey a powerful Native message. His search was successful, in identifying the voyaging canoe Hokule'a as symbolic of Native Hawaiian ocean-going innovation and cultural perseverance, strength, health, and the renewal of traditional Hawaiian culture.

The original Hokule'a was built according to designs by Herbert Kawainui Kane (Native Hawaiian), based on his thorough study of the history and seafaring of the South

Photo 2. Dr. Lindberg on a training cruise of the full-size double-hulled Hawaiian voyaging canoe Hokule'a, Pacific Ocean a few miles west of Honolulu, Oahu, HI, 2009.

Pacific Islanders. Kane envisioned a double hulled canoe that could make the voyage from Polynesia to Hawaii using traditional sailing methods, navigation, and seafaring skills. The Hokule'a successfully sailed from Hawaii to Polynesia and back in 1976, thus proving that such a voyage was possible.

Dr. Lindberg and a small group of NLM staff were honored to be invited on board for a training cruise on the Hokule'a in February 2009.

Fortuitously, as it turned out, just prior to the cruise, Dr. Lindberg was able to interview Nainoa Thompson (Native Hawaiian), a master navigator and President of the Polynesian Voyaging Society (PVS). The PVS is the leading organization that sponsors the Hokule'a voyages. Mr. Thompson explained the powerful imagery of the Hokule'a in the renaissance of Hawaiian tradition, culture, and hope for the future. For further

information on the PVS, and for background reading on the Hokule'a and double-hulled canoes, see [22-24].

After the cruise, Hardy Spoehr, then executive director of the Papa Ola Lokahi, a leading Native Hawaiian health organization, connected Dr. Lindberg with two of Hawaii's master boat and model makers, Jay Dowsett (Native Hawaiian) and Tay W. Perry. Dr. Lindberg visited their boat yard and was impressed.

Also important, a few months later (May 2009), Dr. Lindberg visited the Hawaii State Art Museum, and was mesmerized by the Herb Kane painting titled "Discovering Hawaii" that was on display. He spent at least 30 minutes studying and admiring this art work. This striking and inspiring painting depicted what Kane envisioned as the discovery of Hawaii many centuries earlier by Polynesians in a double hulled oceangoing canoe like the Hokule'a. Days later, Dr. Lindberg visited the boat yard again, and made the decision to commission Dowsett and Perry to build a one-sixth scale model of the Hokule'a for display in the Native Voices exhibition.

Struck by the majesty and cultural power of Herb Kane's paintings, Dr. Lindberg made a point to visit Kane in Sept 2009 on the Big Island. In part due to that visit, NLM was able to obtain Kane's permission to display a selection of original prints in the Native Voices exhibition. The prints were installed on the walls of the NLM main lobby, where the scale model Hokule'a was on display during the Rotunda exhibition. For further information on the Herb Kane paintings and their historical significance see [25]. (The Kane prints are now in the NLM permanent print collection; and the scale model Hokule'a is on long term display on the island of Oahu, Hawaii, under the auspices of the Friends of the Hokule'a and Hawai'iloa, Kailua, HI.)

The capstone of Dr. Lindberg's engagement with the Hokule'a was his and NLM's hosting of a visit by Nainoa Thompson and the Hokule'a crew to NLM in May 2016. This was on the occasion of the Hokule'a stop at the Washington DC area while on its Mālama Honua (to care for our Island Earth) World Wide Voyage, and its leg sailing up the East Coast of the U.S. [26]. The Hokule'a docked at the Washington Boat Club on the Potomac River. NLM partnered with Darlene Kehaulani Butts (Native Hawaiian), President of the Hawaiian Civic Club of Washington, DC, to host a special NLM website on the Hokule'a visit and schedule, including a major event at NLM.

Mr. Thompson made a powerful and inspirational illustrated presentation to a standing room audience in NLM's Lister Hill Auditorium. Mr. Thompson conveyed the cultural and ecological significance of the Hokule'a journey for Hawaii and the world. A follow up luncheon gave Dr. Lindberg an opportunity to personally honor Thompson, his amazing team of navigators and crew members, and the aspirations for a healthy and peaceful planet symbolized by the Hokule'a voyage. A videotape of Thompson's NLM presentation remains available [27].

9. Healing Totem Pole

In late 2010, Dr. Lindberg asked if another iconic element could be added to the exhibition? A full-size totem pole was one of the options he favored, as the totem pole is highly respected by Alaska Natives, American Indians, and Native Hawaiians. The totem pole is a powerful symbol of Alaska Native and American Indian spirituality, healing, and strength, and this heritage is shared with Native Hawaiians. A plan emerged to commission a new totem pole since the initial idea to loan an original totem pole was not feasible.

Photo 3. Healing Totem Pole installed next to the NLM Healing Garden, totem carved by a Lummi Nation carving team and traveled by truck from Washington State across the country to Bethesda, MD, 2011.

Kathy Cravedi volunteered to research the options and eventually proposed that NLM commission the carving of a smallish full-size totem pole. Cravedi identified a tribe (the Lummi Nation of Bellingham, WA) whose carvers had experience in harvesting a suitable downed red cedar tree, carving the totem, and transporting a totem by truck across the country. (The same group carved the 9/11 memorial totems installed on the U.S. East Coast.)

The Native Voices Healing Totem was commissioned in Spring 2011 and carved by Jewell "Praying Wolf" James and his House of Tears carvers at the Lummi Nation in Bellingham, WA. The totem pole was trucked across the U.S., with stops at tribal or cultural locations for blessings along the way. Appendix 6 provides a list of totem stopovers. Dr. Lindberg attended the totem journey blessing ceremonies at the Lummi Nation tribal sacred lands at Semiahmoo, WA. and in Seattle WA. in August 2011.

The Healing Totem Pole carved for NLM was installed adjacent to the NLM healing garden in late September 2011 just prior to the exhibition opening. It remains on long-term display on NLM's grounds, and with the healing garden, continues to offer a meditative and respite space to NIH employees and the public.

On his last trip to Alaska as NLM director, Dr. Lindberg visited the Totem Pole National Historic Park, U.S. National Park Service, in Sitka, AK [28]. The extensive totem pole collection and the towering majesty and strength of the totems on behalf of Native culture, healing, and longevity deeply impressed him. For further discussion of the multicultural significance of totem poles, see [29].

10. Traveling Native Voices

Dr. Lindberg sought to create a traveling version of Native Voices, as was done with several earlier NLM exhibitions. Hence, the exhibition team converted the content and displays of the Rotunda presentation into a six-banner, six-iPad traveling exhibit. The banners covered the major themes of the Rotunda exhibition through carefully selected text, photos, and images combined with the iPads for accessing the video interviews. For videos and photos of the traveling exhibit, see [30].

Dr. Lindberg requested that the traveling exhibit should be pilot tested at selected regional medical libraries and Native venues. Appendix 7 describes four of the regional traveling exhibit opening ceremonies and related field visits where Dr. Lindberg participated.

The NLM traveling exhibit pilot test phase identified various implementation issues that needed fine tuning, as well as opportunities for extended outreach to local Native American and library user communities. For example, the University of New Mexico Health Sciences Library and Informatics Center (in Albuquerque) focused on Native Voices traveling and online versions, which reached several tribal college and tribal serving university libraries in New Mexico [31].

The full Native Voices traveling exhibit tour included over 135 venues in 40 States, some managed directly by NLM, and the majority managed by the American Library Association (ALA) under contract to NLM.

In November 2015, the ALA conducted a nationwide call for proposals to host Native Voices. After review, the ALA selected 104 venues including college, university, public, and tribal libraries from 40 different states. Ninety-four venues were completed, with the remaining 10 venues cancelled due to COVID-19 or other building restrictions. The combined estimated exhibit attendance across all completed venues was several hundred thousand persons and estimated combined attendance at related events was about 28,000 persons.

Each venue held an opening event and at least one special event. Host venues were encouraged to involve local tribal groups in event planning, and many venues did. Twelve tribal libraries participated, with a combined exhibit attendance of about 6,000 persons, and special event attendance of about 8,000.

11. Conclusions

The Native Voices project was a transformative and capstone activity for Dr. Lindberg and several of the core project staff. For Dr. Lindberg, this project helped fulfill his desires to reach out to Native Americans and provide a way to respect and honor Native views of health, wellness, and illness. He believed this would help empower Native health and improve non-Native understanding of how Native health concepts work, and how they could contribute to and complement Western healing models. It was the hope of NLM's Native Advisors that Native Voices also would help inform Native youth about Native medicine and how Western and traditional medicine can work together to advance Native health and wellness.

The response of the Native advisors and leaders was overwhelmingly positive. Some interviewees who had been uncertain about the project were very pleased with the results. The Native advisors promoted Native Voices in their own communities and arranged or encouraged individuals or groups from Native and other relevant organizations to visit the Rotunda exhibition in Bethesda MD or online. The exhibition and the outreach work leading up to it even caught the attention of Congress. U.S. Senator Daniel Inouye, Hawaii, had urged NLM in Congressional report language to document Native Hawaiian healing traditions. Now it was done.

For additional observations and reflections of key Native advisors, please see the companion chapter in this book [32].

Native Voices had an intensified and positive impact on Native locations where site visits and interviews were conducted. This includes the local areas where Listening Circles and Tribal Consultations were held, and from which participants were drawn. The impact included aforementioned site visits and video work associated with the Hokule'a and Healing Totem Pole.

Only a fraction of all Indian tribes and Native villages were included in the project, due to financial and time constraints. To further diversify, the Native Voices team added interviews to reflect Native youth and other geographic areas, and art and artifacts from diverse Native culture groups. A website search function was added to search for all tribes mentioned across all website elements, such as interviews, special events, art works, and the interactive timeline which, as noted earlier, includes 460 Native-related historical factoids and/or images covering antiquity to the present day. The website search function identifies 168 different tribal or Native groups mentioned in Native Voices, which suggests extensive coverage.

However, the broader impact of Native Voices on the public was harder to assess. The traditional indicators suggest a greater than average impact relative to other NLM exhibitions, based on the number of groups visiting in the first year or two after opening, user feedback during the traveling exhibit pilot testing, visitor estimates associated with the ALA managed phase of the traveling exhibit, and website usage estimates.

The greatest opportunity for future impact may be the use of the Native Voices videos and other materials as an educational resource. The size and robustness of the video database suggests the need for significant user time and effort to extract their educational value. A learning environment may be most compatible, such as is offered at the middle school/high school and college and university levels, including tribal and tribal serving colleges, in history, health, sociology, cultural, art, language, and related studies.

The spirit of Native Voices is admirably presented in the exhibition opening video [33]. This finally honed video weaves together many of the themes and topics in this

chapter: the key role of Native Advisors; the iconic Hokule'a and Healing Totem Pole; the importance of Native ceremony and healing; the linkages to Native art and artifacts; and the use of touch screens, iPads, and the website for presenting the Native videos.

While the Rotunda and traveling version of Native Voices have concluded, the website continues to provide access and advance Dr. Lindberg's capstone outreach activity. The full-length Native Voices video archive in the NLM permanent collection also may serve research needs. These possibilities provide an enduring reminder to the authors of Dr. Lindberg's commitment, compassion, and caring for the health and wellness of Native Americans.

Finally, it should be emphasized that Dr. Lindberg appreciated the need to make the multiple visits, enumerated in this chapter, to the Native communities whose people, leaders, and cultures are at the core of the Native Voices exhibition. The hosts saw his personal involvement as evidence of respect and a genuine interest in listening and learning, and it became the basis for establishing a relationship based on mutual trust. The latter provides a model for health leaders who seek to gain the trust of minority communities whose suspicions of motives and memories of past injustices cry out for real and repeated engagement.

Some of the NLM staff not otherwise mentioned are listed on the Native Voices credits page [7].

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Appendices

Appendix 1. Listening Circles with Native Leaders Held by NLM in 2003-2004

- Dakota/Lakota American Indians, hosted by Standing Rock Sioux Tribe, ND, August 2003, organized by Dr. Cynthia Lindquist, President, Cankdeska Cikana Community College, Spirit Lake Dakota, Ft. Totten, ND, and Pamela E. Iron (Cherokee/Laguna Pueblo), Executive Director, National Indian Women's Health Resource Center, Tahlequah, OK. Field visits to the Sitting Bull Tribal College, and Standing Rock Tribal Headquarters, ND;
- Native Hawaiians, hosted by the University of Hawaii at Manoa, Center for Hawaiian Studies, February 2004, organized by Hardy Spoehr, then Executive Director, Papa Ola Lokahi, Honolulu, HI;
- Alaska Natives, hosted by Southcentral Foundation (SCF), Anchorage, AK, August 2004, organized by Dr. Ted Mala, SCF. Site visits to the Alaska Native Heritage Center, Anchorage, the Regional Medica Center in Kotzebue, AK (just above the Arctic Circle), and the Buckland Native Village and School (and boyhood home of Native Advisor Dr. Mala), a typical small remote village similar to where many Alaska Natives still live today.

Appendix 2. Tribal Consultations with Native Leaders Held by NLM in 2006-2011

- October 2006/Alaska Natives, consultation hosted by Southcentral Foundation (SCF), a Native health services organization, Anchorage AK, organized by Dr. Ted Mala, Director of Traditional Healing and Tribal Affairs, SCF, and John

Scott, President, Center for Public Service Communication (CPSC). Video recorded with assistance by a locally arranged video studio. Field visits by NLM staff to the University of Alaska at Anchorage, and the Alaska State Library and Alaska State Legislature, Juneau, AK.

- December 2006/American Indians, Santa Fe, NM, organized and hosted by Holly S. Buchanan, M.Ln., MBA, Ed.D., then Director, University of New Mexico Health Sciences Library and Informatics Center (UNM HSLIC), Albuquerque, NM. Field trips to several New Mexico pueblos, including Taos Pueblo and its Native arts center, Acoma Pueblo, a pueblo on top of a mesa with a cultural center below, Jemez Pueblo known for its wood kilned pottery, and the Laguna pueblo public library, and to the Institute of American Indian Arts tribal college, Santa Fe, NM.

- June 2008/Urban Indians, Seattle, WA, organized by Ralph Forquera (Juaneño Band of California Mission Indians, Acjachmen Nation), Executive Director, Seattle Indian Health Board (SIHB). Day long consultation, with the first set of video interviews by APDB using high-definition video format. Dr. and Mrs. Lindberg led the NLM delegation on site visits to the SIHB medical, dental, and senior citizen centers.

- February 2009/Native Hawaiians, more than 30 interviews conducted on the islands of Oahu, Moloka'i, and The Big Island. The visits were organized by Hardy Spoehr, then Executive Director, Papa Ola Lokahi, and Marjorie Mau M.D. (Native Hawaiian) and Kalani Brady M.D. (Native Hawaiian), both of the University of Hawai'i John A Burns School of Medicine (JABSOM). The trip commenced with a daylong visit to the Waianae Coast Traditional Healing Center, and its expansive Healing Gardens. The NLM team then visited the Native Hawaiian Health Center on Moloka'i; Kalaupapa Hansen's Disease Settlement and its Medical Center, also on Moloka'i; and Hawai'i Island's Native Hawaiian Health Care System headquartered in Hilo (known as Hui Malama Ola Na'Oiwi). Also included was a visit to the Miloli'i Native fishing village on the Big Island, where NLM and Papa Ola Lokahi had implemented a project to provide the first ever Internet service and computer lab to the village library. Back on Oahu, NLM visited JABSOM for interviews, and then Dr. Lindberg and some staff participated in a Training Cruise of the Polynesian Voyaging Society's traditional double hulled sailing canoe, the Hokule'a.

- May 2010/Mississippi Band of Choctaw Indians, Choctaw, MS and Jackson, MS. Organized and hosted by Kenneth York, Ph.D., Planning Director, Mississippi Band of Choctaw Indians, Choctaw, TN. Visits to the Tribal Headquarters, health clinic, museum & cultural center, stickball field, and traditional dancing.

- April 2011/Bismarck & New Town, ND. Bismarck included interviews with Native healers and Medicine Men from the Dakotas, organized by Cynthia Lindquist Ph.D., President, Cankdeska Cikana Community College, Spirit Lake Dakota, and also attendance at a meeting and powwow of the American Indian Higher Education Consortium, chaired at the time by Dr. Lindquist. New Town included interviews and site visits organized by Richard Mayer, Tribal CEO, Mandan-Hidatsa-Arikara (MHA) Nation (also known as Three Affiliated Tribes). Visits to health, education, culture, museum, and tribal council sites at the MHA Nation.

- Dr. Lindberg conducted additional video interviews at the NLM video studio, Bethesda, MD. These included, for example, U.S. Senator Daniel K. Inouye, Hawaii; Yvette Roubideaux, M.D., M.P.H. (Rosebud Sioux), Director, Indian Health Service, U.S. Department of Health and Human Services; Benjamin Young, M.D. (Native Hawaiian), Professor Emeritus, JABSOM, University of Hawaii, and ship's doctor on the return leg of the first Hokule'a voyage; and Code Talker Thomas H. Begay (Navajo) and Nonobah Begay.

Appendix 3. Distribution of Native Voices Video Clips by Theme and Topic

Theme: Community. Hear why connections between families and communities are vital for Native health and wellbeing.

Topics (number of clips in parenthesis—total clips 74): Attitudes (12); Boarding Schools (6); Diseases/Disorders (12); Education (10); Kalaupapa (9); Medical School (4); Reservation Life (15); Urban (12).

Theme: Healing**.** Examine the Interaction between traditional and western medicine in Native health today.

Topics (total clips 68): Beliefs (13); Diet & Nutrition (6); Healers (10); New Ways (21); Old Ways (18).

Theme: Individual**.** Learn how Native Peoples are striving for Healthier lives.

Topics (total clips 54): Family (10); Identity (17); Personal Responsibility (21); Role Models (7); Tribal Ties (9).

Theme: Nature**.** Explore Native Peoples' respect for the natural world.

Topics (total clips 48): Art (6); Environment (6); Higher Power (9); Land (17); Plants (5); Water (5).

Theme: Tradition**.** Study Native heritage and the legacies that continue to enrich daily life.

Topics (total clips 44): Ceremonies (10); Creator (4); Death & Burial (8); Elders (4); Ideas (12); Language (6).

Grand total 288 video clips across all 5 themes.

NOTE: For illustrative examples of video clip content, please see Appendix 4.

Appendix 4. Verbatim Native Voices Video Clips that Illustrate All Five Exhibition Themes

The verbatim transcripts of a small cross section of selected video clips are shown below, organized by each of the five overarching themes of the video clip collection.

Community:

Ted Mala, M.D., M.P.H., Alaska Native/Inupiat Eskimo.

No Role Model: I think a lot of us that went to boarding school had a lot of family problems. We had no way to relate. We had no role models. It was—had a lot of trail of tears, also. But the history of the world is that of people doing what they think is right? I mean look at Stalin, look at Hitler, look at everybody that thought that they were on a mission from God and doing the right thing and people did that, the missionaries and the military and the educators and so on, came to Alaska, did the same thing. They all thought they were doing a great thing. You can't live in that sod house; you need a HUD house, and the first HUD houses that came up to the Arctic were trailers, and the trailers were lowest-bid trailers, and not only were they lowest bid, they were made in California, and

it was cold as hell when the wind blew through in the Arctic. It would be great in Palm Springs. So again people were doing what they thought was right and all of a sudden we found ourselves going from subsistence economy to cash economy.

Cynthia Lindquist, Ph.D., President, Cankdeska Cikana Community College, Spirit Lake Dakota.

Tribal Colleges: We try to set up posters, and we try to do the dual images with our regalia, you know, really personifying us as Native or indigenous people, but then also with the stethoscope, or the white jacket and that, and we can do this. We can accomplish this, and that's one of the wonderful things about tribal colleges is that we try to utilize and tout the role models who are out there in education, but especially when we talk about math or sciences, we try to relate it back to culture.

Ralph Forquera, American Indian/Juaneño Band of California Mission Indians/Acjachmen Nation), Executive Director, retired, Seattle Indian Health Board.

Displacement: The displacement of Native people to cities has had a profound effect on their psyche, how they see the world, how they view the world, their ability to trust people, their ability to interact in a way that allows us to be able to instill in them a sense of belonging, a sense of well-being that can translate then into better health. And the work that we do, while we provide medical and dental services and all the clinical care that I think most people associate with a health care system, the role that we've really played in this community is one of acceptance, bringing people together. Being an institution that allows for people to self-identify as being a Native person and for us not to be judgmental in the process of that.

Healing:

M. Kauila Clark, Traditional Healer, Native Hawaiian.

Healing Power: The key component in all healing process - and I really don't - it's a misnomer for me to claim to be a healer, because the healing is really done by the Creator, and at best I'm a facilitator of energy from the Creator in the universe and trying to put together a healing power so that people can be healed. So a lot of what we do is we're trained to go through meditation, and prayer, and so a lot of what we do is in the mode of prayer, calling upon the universal energies to facilitate what needs to be done in the healing process.

Kenneth H. York, Ph.D., American Indian/Mississippi Band of Choctaw Indians.

Native diagnosis: My dad used to say the woodpecker taught some of our Native healers. The woodpecker would peck the tree when it's dying, and before it dies, the woodpecker finds that problem which normally is the insect inside the tree, so they would pull that out. So the Native healer would do the same thing. They would feel your body and find the problem, and then they would extract that problem.

Robert Fortuine, M.D., US Public Health Service, retired, Alaska historian

Shaman: Originally, Native healers as I see it, were in two major groups. There were the shamans and the magical healers, you might say, that have counterparts all over the world, really, and then you have sort of empirical healers who are the ones who massage, who do bleeding, who do minor surgical procedures that take care of simple illnesses like colds and burns and whatnot, which are not caused by angry spirits or something like that.

Individual:

Charles Nainoa Thompson, Master Navigator, Native Hawaiian, President, Polynesian Voyaging Society.

Pride: When I was born, when I was raised, to be Hawaiian meant to be second rate. These kids when they're born, they don't feel that or sense that. Their foundation they

grow from is different. But, you know, the economic, the social, the health—those issues, those statistical issues which are lagging issues, haven't necessarily really changed. But the genesis of the child being born in Hawai'I - the difference between being depressed or proud has shifted.

Katherine Gottlieb, MBA, DPS, Alaska Native/Aleut/Sugpiaq.

Men's Roles: We're trying to get more and more men involved because our Native men are still leaders in our communities. In order to get into a community, we have to work with our men. And, also, I think the strength behind what our men have in the core of them, if it's brought out, they can be the protectors, and that's why it's called the Warrior's Initiative, because of in days of old they would stand, and they would protect their families. They would die for their women and their children. And what we're saying is do that again. Come back and do it today, and this time do it around domestic violence, child sexual abuse, and child neglect. End that for us as strong men and warriors just like they did in the days when they had to stand up and fight for us. We want them to do it today.

Nature:

Kamaki A. Kanahele, Traditional Healer, Native Hawaiian.

Already Medicine: Everything about us is already medicine: the earth, the sun, the sea, the mountains, the plants, everything that has been given, is healing.

Chief Arvol Looking Horse, Spiritual Leader of the Great Sioux Nation, American Indian/Mni Coujou Lakota.

Mother Earth: In our life everything has to come from alive, the, the medicine. Even the Sundance tree has to be a live tree that gave its life for the people to live, and that Mother Earth is a living spirit, so I made a statement saying that Mother Earth is a source of life not a resource.

Tradition:

Thomas H. Begay, Navajo Code Talker.

Enemy Way Ceremony: Of course, I had a ceremony because I come from traditional. We have ceremony before you go to war. I have ceremony when I was a young man. Way back, five or six years old, I had the Animal Way Ceremony because my relatives were having it, so they have to use me as, you know, part of the ceremony. Then I went to war, and then came back and had another ceremony.

Britta Guerrero, American Indian/San Carlos Apache.

Respect: I'm accountable to my Aunties, I'm accountable to my elders in my community, and if they see me doing something that is hurtful to myself or others, then I can be called on that. When you're part of the Native community you play a part, there is a role for you, and you know people there to tell you that you have to answer to them. I think it's expected when we are very dispersed and we are not engaging each other, you're able to do things without someone telling you, and you may not know that you're making a bad choice, but when you've got people holding you to a higher standard, and they tell you something, you have respect for them, and you want to make sure that you heed their words and that you follow in their footsteps and that you don't disappoint them.

Appendix 5. Additional Examples of Native Voices Art and Artifacts

- Dr. Lindberg also supported commissioning of new Native art works where appropriate, such as a set of ceremonial regalia (pipe, fan, drum, drum stick and rattle) from the MHA Nation; Native healing plants from Native Hawaiian

cultural practitioner Kahu Kauila Clark (e.g., Aloe, Plantain, Banana) and Mescalero Apache Medicine Man Paul Ortega (e.g., Yucca, Mescal, Mesquite); a Koa wood spiritual sculpture also from Kauila Clark; and an original Medicine Wheel painting "Spirit of Eagles" by Cree Indian artist Chholing Taha.

- In addition, the exhibition included a special art gallery curated by the late Milton W. Corn, M.D., of NLM, that included rotating paintings on loan from the Philbrook Museum of Art, such as: "Choctaw Sick Dance," Terry Saul, no date, watercolor; "Navajo Healing Rite," Jimmy Toddy,1954, watercolor; "Osage Peyote Man," Carlton Delmar Woodring, 1958, watercolor; "Water Ceremony," Franklin Fireshaker, Ponca, 1970, watercolor; and "Burning of the Cedar," by Woody Crumbo, Potawatomi, 1946, egg tempera on muslin.
- Exhibition photos from various sources included, for example, "Eskimo high kick ball," 1914 (courtesy Alaska State Library); "Choctaw world stickball championships," 2009; "Billy Mills (Oglala Lakota) winning the 10,000 meter race, Olympic Games, Tokyo, 1964" (courtesy US Marine Corps); "Billy Mills as a student athlete at Haskell Indian Nations University," 1956; "Grand Medicine Lodge and Ojibway Chief," White Earth Indian Reservation, MN, 1910 (courtesy Minnesota Historical Society); "Oglala Lakota Indian Holy Man Black Elk Praying on Harney Peak, Black Hills, SD," 1931 (courtesy State Historical Society of Missouri and John G. Neihardt Trust); "Michael Hackwith, USMC Ret., Lakota Spiritual Leader and Sweatlodge," 2010, (courtesy U.S. Air Force/Monica Mendoza).
- Some additional photos: "Cheyenne Indians at a Sun Dance," Edward S. Curtis, c 1910 (courtesy Library of Congress); "Nez Perce and Umatilla Indian Men and Women Gather for a Powwow, with Drum Group," c 1900, (courtesy Northwest Museum of Arts and Culture); "Mashpee Wampanoag Indian Powwow," Mashpee, MA, July 2010 (courtesy Bryant Pegram/NLM); and "Return of the Hokule'a" from her round trip voyage to Tahiti, Waikiki, Oahu, 1976 (courtesy Benjamin Young, M.D./Monte Costa).

Appendix 6. The NLM Healing Totem Blessing Stopovers - West Coast to East Coast (U.S.)

- Semihamoo, WA, spiritual ceremony, original Lummi Nation lands
- Seattle, WA, near the Space Needle, journey kick-off ceremony
- Arlee Powwow Grounds, Flathead Indian Reservation, MT
- Little Big Horn Monument, near the Crow Nation, MT
- Wounded Knee Memorial, Pine Ridge Indian Reservation, SD
- Sitting Bull Tribal College, Standing Rock Sioux Tribe, Ft. Yates, ND
- Cankdeska Cikana Community College, Spirit Lake Dakota, Ft. Totten, ND
- White Earth Tribal and Community College, White Earth Nation, Mahnohem, MN
- Ho-Chunk Nation, Black River Falls, WI
- American Indian Center of Chicago, IL
- Onondaga Nation School, Nedrow, NY
- Mohegan Tribe, Uncasville, NY

- Arrow Park, Site of the Lummi Nation 9/11 New York Totem Pole, Monroe, NY
- National Library of Medicine, Bethesda, MD.

Appendix 7. Native Voices Traveling Exhibit Opening Ceremony Venues

- October 2013, at the Cankdeska Cikana Community College, Ft. Totten, ND, with participation of Dakota medicine men and healers, in conjunction with an Education and Art Week - included a tour of the tribal college, and the Valerie Merrick Memorial Library and its Donald A.B. Lindberg Resource Room, which also serves as a community library and Internet access point for the local Spirit Lake Dakota tribal area. When the NLM closed its Rotunda exhibition in Bethesda, MD, the Native Voices bookshelf collection was donated to this tribal library.
- June 2014, at the Anchorage Convention Center, sponsored by the Southcentral Foundation, and in conjunction with the annual summer meeting of the National Conference of American Indians - included subsequent visits to the SCF Native Primary Care Center and the WWAMI Medical School branch at the University of Alaska, Anchorage, and a visit to the Alaska Native Heritage Center, where the traveling exhibit was moved and set up immediately following the opening days at the convention center.
- July 2014, at the Queen's Medical Center, Honolulu, HI, in conjunction with the annual Queen's Heritage Day, celebrating the founding of the Queen's Hospital by Hawaii's King Kamehameha and Queen Emma, and co-sponsored by the Queen's Native Hawaiian Health Program. Special speakers included U.S. Rep. Tulsi Gabbard, and Benjamin Young M.D., the ship's doctor on the maiden Hokule'a voyage, and an NLM advisor. Subsequent local Native Voices traveling visits included the Health Sciences Library, John A. Burns School of Medicine, Hamilton Library at University of Hawaii at Manoa, Kapiolani Community College Library, and University of Hawaii at West Oahu Library.
- August 2014, at the Chickasaw Nation ARTesian Gallery & Studios, Sulphur, OK—included subsequent site visits to the Chickasaw tribal headquarters, Chickasaw Hospital, Chickasaw Health Information Center, Chickasaw Health Clinic, Chickasaw Cultural Center, and the historic Chickasaw National Capitol.

Reflections on Dr. Donald A.B. Lindberg and Native Voices

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Abstract. Personal reflections on Donald A.B. Lindberg M.D. are offered by four Native American leaders who were instrumental in the successful development of the National Library of Medicine's (NLM) *Native Voices Exhibition: Stories of Health and Wellness from American Indians, Alaska Natives and Native Hawaiians.* A uniquely collaborative effort, the exhibition features nearly 100 videographed interviews conducted by Dr. Lindberg with Native elders, healers, leaders, and people. He is credited with the incorporation of indigenous peoples' healing knowledge in a personal and relational way, making for a wonderful journey together that was a very large chapter in his life and that of the authors.

Keywords. U.S. National Library of Medicine, Donald A.B. Lindberg M.D., American Indian, Alaska Native, Native Hawaiian, Indigenous People, Native Healing, Native Voices Exhibition

1. Introduction

A companion chapter in this book, *Native Voices Exhibition: Stories of Health, Wellness, and Illness from American Indians, Alaska Natives and Native Hawaiians* details the origin, development, implementation, and celebration of a most unusual exhibition undertaken under the leadership of Donald A.B. Lindberg M.D., Director of the U.S. National Library of Medicine (NLM) [1]. Native Voices was a highly visible and frequently visited presence from 2011-2015 at the NLM, located on the campus of the National Institutes of Health (NIH) in Bethesda, MD. Traveling versions subsequently visited locations throughout the U.S. from 2013 to early 2020. An online version continues to be accessible on the Native Voices website where videographed interviews and other exhibition resources can be found [2].

The Native Voices exhibition was a technical and human achievement that told a remarkable story, largely unknown to many, of Native health and wellness. At its core, it is told in the Native voice as personal videographed interviews conducted by Dr. Lindberg with more than 80 elders, healers, and community leaders. They are representative indigenous peoples - American Indians, Alaska Natives and Native Hawaiians, who live in diverse tribal lands, reservations, villages, and urban communities.

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Scores of artifacts enhanced the exhibition, and two symbolic icons delivering powerful messages of Native healing were commissioned. A scale model of the Hokule'a, the Native Hawaiian voyaging canoe occupied a place of honor in the NLM lobby and has since been repatriated to Hawaii; the Healing Totem crafted by an indigenous carver in Washington State sits permanently near the NLM entrance.

Dr. Lindberg, along with his NLM outreach team, earned our trust through multiple visitations organized as Listening Circles, Tribal Consultations, and as purposeful individual trips of special interest to, for example, remote Indian reservations in North Dakota and elsewhere; two comprehensive health centers designed for indigenous peoples in Anchorage and Oahu offering both western and traditional medicine; an Alaskan Innuit village in the Arctic Circle, and a Hansen's disease enclave on Kalaupapa, Hawaii. The latter two destinations are accessible only by small plane. In the end, it was Dr. Lindberg's sincerity of purpose to tell our story accurately, respectfully, and empathetically that encouraged us to work with him and to facilitate access and cooperation by others.

2. Our Personal Reflections

As this book project took form, Elliot R. Siegel Ph.D., the editor of the Outreach Section approached us with a request to contribute a chapter that would complement the Native Voices exhibition chapter. (Dr. Siegel was a lead member of Dr. Lindberg's outreach team). Our chapter would serve as a personal recounting from the Native perspective of the exhibition's origins and development, and offer reflections on our experiences with Dr. Lindberg that helped make the Native Voices exhibition possible:

With Dr. Donald Lindberg's passing in 2019, several of his close colleagues are developing a tribute book to Don's memory and accomplishments. Mary Lindberg is an enthusiastic supporter. We envision this chapter to be an opportunity for each of you to come together and tell your stories about your experiences working with Don Lindberg and the NLM outreach team; educating us, opening doors, and helping ensure that the spirit and culture of Native Medicine was accurately portrayed in the environs of NLM and the National Institutes of Health (NIH), a bastion of Western medicine. As editor of the Outreach Section, I leave it to you to shape the chapter as you see fit - it is Don's story as told from your perspective. We know how meaningful this work was to Don, he gave so much of his time, and he learned so much from your teachings.

3. Cynthia Lindquist, Ph.D., President, Cankdeska Cikana Community College, Ta'sunka Wicahpi Winyan (Star Horse Woman) Spirt Lake Dakota Tribe

In remembering Dr. Lindberg, I see a tall, grandfatherly, and unassuming man. Little did I know the breadth of his intelligence, kindness, and insight...or the magnitude of NIH/NLM under Don's leadership. America's medical library was led by this thoughtful leader and he cared about people of color and underserved communities.

During the 1990s I worked for the Indian Health Service and helped to establish the National Indian Women's Health Resource Center, located in Tahlequah, OK. The Executive Director, Pam Iron, and I were approached by Ted Mala M.D. and Dr. Lindberg to organize and coordinate a series of Listening Circles for NLM. Pam, Ted,

and I had come up through the ranks as tribal members involved in tribal health and we understood the need for officials (government, public, or private) to be engaged at the community level - to really 'listen' to the people prior to setting up programs or services. Dr. Lindberg heard Dr. Mala's insight and readily agreed... thus three Listening Sessions were held in indigenous country - the Great Plains, Hawaii, and Alaska. Our intent was to demonstrate the diversity of indigenous peoples and communities.

Dr. Lindberg and his team of professionals were engaged and they did 'listen'! Each Session was organized by a group of local health workers and elders but also with elected tribal officials. The goal was to hear from the indigenous people (the public) directly but also to share general information about NLM as most Natives had never heard of NLM or were aware of what it does. I believe Dr. Lindberg learned that there is commonality in Native communities (history of colonization, policies to force assimilation) but there are also significant differences, particularly with cultural practices, let alone languages. This knowledge led to better engagement within the NLM system for their outreach and services to minority communities.

While Natives tend to be very suspicious of the "Great White Father" mentality of the federal government - and that sentiment lingered with the Listening Sessions - Dr. Lindberg's follow up (i.e., sending computers and books to the very rural, isolated community libraries visited) was efficient and timely. I believe that the Listening Sessions were the foundation for the Native Voices exhibition.

Dr. Lindberg also took to heart my concern that he had not heard enough from traditional healers (medicine men) and thus arranged for a series of interviews during the annual tribal college student conference in Bismarck, ND in 2011. Seven healers from the Northern Plains, including one from Canada, were interviewed by Dr. Lindberg about healing arts, sustainable development, behavioral health, death, and other topics.

These interviews, along with the others, are now history as part of the Native Voices exhibition. Indigenous communities have suffered significant losses due to the current coronavirus pandemic and the Native Voices exhibition, information, and materials will be a resource of knowledge for our recovery.

Cankdeska Cikana Community College (CCCC) hosted the initial opening of the Native Voices traveling exhibition in 2013. While Dr. Lindberg and his wife Mary were visiting - for the second or third time - we showed them the Don Lindberg Resource Room in the Valerie Merrick Memorial Library that is operated by CCCC. NLM provided CCCC with funding throughout the years to provide internet access for our community. Don was quiet and appreciative, demonstrating his humility that is a core Dakota value. We wanted him to know that his support and monetary contribution made a difference and impacted Native lives.

My opinion of Dr. Lindberg is that of a person who takes the time to listen, to learn, and then to use his position of authority to make things happen. He did good work in a responsible manner and tried his best to affect change where he could. Dr. Lindberg is remembered in a good way as a good relative. His legacy will be noted by our grandchildren and great grandchildren - this is a high Dakota honor.

I am blessed and a better person to have known and worked for Dr. Don Lindberg.

4. Theodore A. Mala M.D., M.P.H., Director of Traditional Healing and Tribal Relations, Southcentral Foundation (retired)

There are few and far between occasions when one stumbles upon greatness in the form of kind and gentle and learned men in various walks of life. Such was my experience in the 1980's meeting Dr. Donald Lindberg, the newly minted library director of the National Library of Medicine at the U.S. National Institutes of Health in Bethesda, MD.

At that time I was an Associate Professor at the University of Alaska in Anchorage. I was working with Alaska's early Arctic health scholars such as Dr. Earl Albrecht, Dr. Fred Milan and Dr. Robert Fortuine to name but a few. As I made inquiries into the newly created internet called Bitnet, I quickly learned that there was no database of U.S. Arctic Health other than some early anthropological works documenting herbal and traditional Alaska Native remedies. The national research gold standard was the Index Medicus based out of the National Library of Medicine.

The only international publication available was the Journal of Arctic Medical Research based in Helsinki and Oulu, Finland. This journal was primarily Scandinavian and documented work done in Sweden, Denmark, Iceland, Norway, and Finland. The only other works were the proceedings of the Arctic Council and the early meetings of Circumpolar Health.

This body of work not only included Scandinavia but also the United States, the Soviet Union, and Canada. Working with the Alaska Health Sciences library based in Fairbanks and eventually Anchorage, it was obvious that the focus of U.S. public health was centered in the more populous regions such as the equator. The Arctic was ignored for the most part.

Out of frustration, I turned to Alaska's legendary Senator Ted Stevens for help. He was the only one I really knew in Washington, DC. Sen. Stevens asked me to come back to his office the next day. There he brought in Margaret Heckler, the Secretary of Health and Human Services who set up a meeting for me with the new NLM Director, Don Lindberg. Thinking I was only going to meet with him, I was surprised when I arrived at the Director's Board Room to meet not only Dr. Lindberg but also Ms. Betsy Humphreys and a room filled with senior staff.

I stated our case that I felt the Arctic and circumpolar peoples were underrepresented and requested we be included in the Index Medicus database.

Dr. Lindberg agreed we should be included. Then, I will never forget his words to me. "Are there enough publications to represent the Arctic" he asked. I mentioned the Journal of the Arctic Council for starters. Then Dr, Lindberg said: "go make a tree." I replied I would advise our Arctic Health Sciences Librarian Stan Truelson who took up the challenge and ran with it.

Some years later, NLM decided to explore discussions with Native American tribes. They invited Dr. Terry Maresca to join those early discussions in Seattle. She was so involved clinically as a Native physician that she asked me to take her place which I did. Thus, my relationship with Dr. Fred Wood and his boss, Dr. Elliot Siegel was born.

Under the banner of Tribal meetings, Dr. Lindberg empowered his staff to explore the heretofore never documented arena of Traditional Medicine. Some years later at the Native Health corporation under the leadership of Dr. Katherine Gottlieb, Traditional Healing was formally recognized in clinical medicine as an equal contributor to Native Healing complimenting clinical allopathic medicine at the Alaska Native Medical Center. I spent sixteen years as its director.

In the '80's we founded the International Union of Circumpolar Health in Umea, Sweden. Dr. Jens Peter Hart Hanson was our first President. I was its first Secretary General. The Journal of Arctic Medical Research was our voice.

As Dr. Lindberg observed the healing effects of Traditional Medicine, he decided to take it a step further and document and record it for its significant contributions to American Health. We rekindled our friendship and spent much time together in his office and home thrashing out what would result in the NLM's *opus magnus* called "Native Voices."

Being a scholar, Dr. Lindberg wanted to hear and see first-hand the role of Traditional Healing in Indian Country. He brought a film crew with him and documented actual Native healers in their own words. This had never *EVER* been done before. The result was the first attempt to document a system of healing that sustained the first people's health long before western medicine arrived. Dr. Lindberg, in his deep wisdom, did not want to engage researchers to provide a secondhand account of what they observed but rather "let the traditional healers speak in their own words."

This is so significant for Indian Country. We have never been asked to speak in our own words. Usually, Indian Country accounts are in the second or third person. Dr. Lindberg invited tribal leaders and healers to the table to document their words. Native people felt honored to be included. As Dr. Gottlieb once commented, it might not be perfect or the end all resource. However, the idea is to encourage others to stand up and lend their voices to history.

Dr. Lindberg left this incredible historical resource for future generations to learn from. He not only included Alaska but also tribal nations across our country even including Hawaii vis a vis Dr. Marjorie Mau, a clinical scholar and Native Hawaiian.

I am humbled to be included in this writing. Similar to most living historical works, it is but a snapshot in the timeline of Native healing. It is well and alive and continually evolves as times change. It is not to say that one lifestyle is of more value than the other. Rather there are many roads to healing, one complimenting the other. We take what we have learned from our elders passed on from thousands of years of teachings.

Thank you Dr. Don Lindberg for letting us have a voice. You planted the seeds of wisdom for our world to learn from and evolve and grow. You and your legacy in medicine will never be forgotten. And for that we will be eternally grateful.

5. Marjorie K. Leimomi M. Mau M.D., M.S. Professor, Department of Native Hawaiian Health, John A. Burns School of Medicine, University of Hawaii at Manoa, HI

It was important, I believe, for Don Lindberg and the NLM team to gain a deeper understanding of who Native Hawaiians are as a people with a cultural heritage that goes back about 7,000 years ago and can trace its origins to the region of Oceania. This cultural inheritance is distinctly different than other indigenous populations in the U.S. - and yet the story of how Native Hawaiians struggled to hold on to their cultural heritage, language and ancestry is similar to many other indigenous populations who were colonized, minimized, and nearly extinguished by dominant power-hungry countries from Europe and the Americas.

Traditional Native Hawaiian health practices such as medicinal plants, lomilomi (massage) and ho'oponopono (conflict resolution) are still used today alongside the practice of allopathic medicine approaches. Practitioners of traditional medicine for

Native Hawaiians normally meant that the individual was someone who understood how to gather, prepare, and use various plants for healing - from their geographic location. That is, place-based knowledge was an important element of the practitioners' knowledge set. Another foundational element of traditional healing came from whether the "patient" was "open" to and believed in the traditional healing practice. This "readiness" to be healed was an important part of the healing process.

The willingness of our Native Hawaiian leaders and healers stemmed from pre-existing trust and relationships of many of the people interviewed. But it also was dependent on Don's willingness to personally take the time to interview the individuals himself. This clearly showed the level of commitment to getting the project done right and to get it "first-hand" by Dr. Lindberg.

The commitment of resources and actually "showing up" in person as the Director of NLM spoke volumes of the Native Voices project being given the highest priority.

In Hawai'i, we had one incident when one of our younger Native Hawaiian faculty became distraught about what he thought was a racist approach to the interview being led by Dr. Lindberg. This was an unexpected response to come from an intelligent Native Hawaiian person. However, in retrospect, it demonstrated an important generational difference of how the interview questions were posed - and how it can ... for some... make a huge difference. While it was not an error on anyone's part, it highlights how some from a more recent generation interpret the use of words and how they may draw their own conclusions ... showing their own bias ... unconscious bias from a younger Native Hawaiian person.

Our Department of Native Hawaiian Health faculty, some of whom also were cultural practitioners, had a longstanding history of visiting Kalaupapa and were aware of its unique medical history and its lessons for today's health care providers. So, providing access to Kalaupapa was relatively easy. The Hokule'a's inclusion really stemmed from the willingness of the leadership at the Polynesian Voyaging Society to understand the connection between "voyaging" and human health and wellbeing. Of course, Don's love for the ocean and maritime history was a natural assimilation. The interview with Dr. Tamura (a non-Native Hawaiian physician, medical officer) and Nainoa Thompson (Native Hawaiian, navigator and wayfinder) I think was particularly engaging because it spoke to universality of how voyaging offers a broader context for indigenous wellness that goes beyond medical care - but also about indigenous ways of knowing ... like wayfinding ... that remain relevant today.

This ancestral knowledge is precise, reproducible, and generalizable (it works everywhere in the world) and crosses racial/ethnic barriers. Indigenous knowledge is alive and well and rivals some of the greatest scientific discoveries of the modern world.

Seeing the detail and beauty of the Hokule'a model in the lobby of the NLM was a source of incredible cultural pride. It really took your breath away, with its depiction of the waves and sails open to catch the wind! The fact that it was so prominently placed meant to many of us of its prominence of who we were and who we are today! It also spoke volumes for Don's vision to have indigenous people be the center and "heart" of the exhibition. Today, it is displayed in a prominent hotel lobby, and attracts hotel guests and locals alike who are attracted to it for its craftsmanship but also its authenticity ... not to mention the story behind its creation.

At the time of its first launching, it helped heal the Native Hawaiian people by providing an iconic vision of who they were and their rich cultural history as an ocean people. We had lost the sense of WHO we were and Hokule'a helped many to feel that sense of belonging and pride again ... to feel whole again.

The Southcentral Foundation/Alaska Native Medical Center "Nuka" model of care also is a truly remarkable functional and quality health care delivery model. In addition, the Waianae Coast Comprehensive Health Center is a model of Native Hawaiian healing that works extremely well for the Waianae Coast community that serves a large Native Hawaiian population. Both share many parallel features: traditional healers, community-supported and focused on indigenous health and wellbeing. However, the products are distinctly different and are difficult to replicate in other settings and context. I think the take-home message is that a health care model for indigenous populations must be "grown organically" and it needs to engage its users ("customer-owners") and it requires dedicated leadership and of course resources, such as funding and policies that will allow them to integrate cultural practices as part of holistic health.

I recall the day we opened the exhibit at NIH, with so many guests, dignitaries, and NIH leadership present. It was amazing to see an exhibit that was not only visual but also interactive and nearly life-sized and handled with such TLC by the curators and exhibit staff. It really made us proud to be there and to feel that energy and pride. Proud to finally be recognized and to be seen for our indigenous knowledge and cultural practices and how this exhibit would live on… way past all of us.

It was really "moving" to see how NLM and Don Lindberg took the time to share the healing totem pole with as many native communities as possible. Not to mention all the cultural protocol done along the way with healers by its side. It really created the right context and recognition of the spiritual components of the Native Voices exhibition.

I think the amount of work, planning, and execution of the Native Voices exhibition clearly was one of the best examples of the federal government fulfilling its promise to honor and recognize the struggles of both the darker and brighter sides of a painful part of our country's history. It was done with incredible sensitivity, class, and style. I can think of no better person than Don Lindberg to have pulled this off with such resounding success. He really set the standard for any other NIH Institute to follow his incredible example of dedication of time and funds to achieve an extremely high bar for authenticity and told in the first person by Native people themselves.

I completed a traveling exhibit to Charles Drew University in California and a colleague took the exhibit to New Bedford, MA. The response we received at both venues was well attended by community members, students, and in Massachusetts with school children. They were astonished to learn about the "untold" stories of healing and indigenous knowledge - most of all perseverance and it was well received in both places. I received many holiday cards from the group in New Bedford, MA and the group at Charles Drew University were proud to bring the event not just to the library and students/faculty on campus but to open it up to the Native Hawaiian/Pacific Islander community in California. Many *many* connections were made during those visits.

I still refer people to the online Native Voices exhibition I have not been on it for a while - but it is a reservoir of many of our elders' voices ...some who have now passed on - so it is a treasure trove to see these leaders and healers in their own words. It is a national treasure of the U.S.'s indigenous peoples. Mahalo to Don and the NLM team for bringing this resource to us and to firmly placing the stories shared and the objects in the exhibit to the rest of the U.S. and to honor those of us who remain ... it will serve as a resource for many generations to come. Mahalo *mahalo*!!

6. Katherine Gottlieb M.B.A, D.P.S., Katherine Gottlieb Strategies and former President and CEO, Southcentral Foundation

When traveling back on a D.C. trip to visit Congressional delegates and Indian Health Service leaders about Alaska Native/American Indian healthcare issues, Ted Mala M.D. scheduled a visit to the National Library of Medicine in Bethesda, MD. It sounded like it would be an interesting visit, especially since we already had a business connection with the National Institutes of Health who shared the same campus.

When our team showed up at the National Library of Medicine, we were greeted by Dr. Lindberg. As we walked through the security entrance, there was an exhibition display to the immediate right of the library. Before the entrance of the Board room there was a wall of previous and current NLM Board of Regents, Newt Gingrich's smile caught my eye. Dr. Lindberg had arranged for all his executive staff to meet with us with a nice lunch prepared. He was pleasant and engaging, we hit it off immediately!

Don (he insisted we address him this way) asked we introduce ourselves and describe the work we were currently doing. He and his group asked many questions. And then we received a great overview of the work the Library was accomplishing. He described the building structure to us; I was amazed to find out it was designed to collapse to secure and save precious books in case of an attack on our country!

Then we toured the building. Offices were on the same level of the board room and then we moved to the first floor where the lives of famous Women in Medicine were on exhibition. The area was in the center of the first floor, and it captured our attention for more than an hour. The information was displayed with video, pictures, and art. We easily could have spent a day or two visiting the exhibition.

Don led us into the library. We moved into a tiny glass walled room. The room was kept at a certain temperature to maintain the life of the books inside. I was given a book to hold and told it was very old and precious. Once I visited Jerusalem and we were in a tunnel deep under the earth where I touched the wall and realized that it was thousands of years old. I felt the same way holding this precious book. When they said it was worth over $1 million, I quickly handed it back to the care keeper, not wanting to wrinkle or smudge it!

Don led us down through the basement where he showed us his data room, where materials were sent out globally through websites and other means of media distribution. We continued walking through the building and exited. We continued our walk as Dr. Lindberg described campus activities outside of the National Library of Medicine.

Little did I know as we said our good-byes, that the visit would be the start of a multi-year friendship. This is Dr. Lindberg, the amazing relationship builder. We graced the Lindberg's beautiful, warm home, guests of his wonderful wife, Mary. He had me appointed by the President, where I served four years as the first Alaska Native person on the National Library of Medicine's Board of Regents. I spent four years of an amazing educational journey about global health and wellness, met amazing people, approved many of the innovative creative means of connecting NLM to the nation. Don created a means for people to gain knowledge about the achievements of NLM - he invited people to become "Friends" of NLM. During the Friends gatherings, he featured speakers tied to a wonderful dinner event filled with opportunity to network and build new relationships.

One of the best innovative ideas Dr. Lindberg devised was Native Voices. I personally enjoyed how he organized working with the tribes, tribal organizations, and tribal leaders around the project. He wisely asked advice from leaders like Dr. Mala

before beginning the project. Dr. Lindberg requested, asking permission to engage in a Region from the local people prior to starting his work.

The feedback from the area was that he was respectful and honoring in the way he moved forward. Even his questions during the interview were all well thought out. During my interview, I felt at ease, without tension or worry about the outcome. As I spoke in depth from a personal and professional view, I felt my words would not come back to haunt or harm the Alaska Native people I served, nor myself or family.

The product of the Native Voices, I viewed as a success. It captures historical views that may not be written anywhere else, with real people and personalized story. Dr. Lindberg's rolling out of the final product was also a marvelous experience where he carefully displayed the work as one of his exhibitions in the National Library of Medicine. Southcentral Foundation was highlighted for health innovation and the work achieved through Dr. Mala for traditional healing.

When NLM took Native voices on the road, it was successfully highlighted at the Alaska Native Heritage Center where local people and visitors from throughout the world received this innovative historical education of the Alaska Native, American Indian, and Hawaiian cultures.

The intent of Dr. Lindberg's engagement with the Indigenous people was to expand the outreach activities of the NLM. The National Library of Medicine wanted more outreach. It makes me smile at the thought. NLM's outreach stretched across the U.S. to be very inclusive, not missing or excluding any Indigenous open invitation. It not only served to connect people to NLM but to connect many of the cultures to one another. The achievement of Native Voices not only educated and connected everyone to the National Library of Medicine, but it also served as an educational tool for each culture to learn of one another.

The intent and accomplishment of Native Voices reflected Dr. Lindberg's integrity and creative genius. His natural ability was to connect with people, earning trust with his non-assuming character. This opened the door for tribal leaders to willingly share personal stories and highlight the strengths of diverse cultures. Dr. Lindberg deserves all the recognition and rewards he has achieved during his lifetime and our thanks.

7. Conclusion

Dr. Donald Lindberg's Native Voices exhibition is a wonderful legacy, it is a successful educational journey told in traditional story form that will continue to educate people down through the generations about the Alaska Native, American Indian, and Native Hawaiian people. Dr. Lindberg listened to council of traditional leaders. He engaged from the heart, was gentle and inviting. A scholar with high integrity, he won the trust of the people.

It was an honor to know him. This chapter is written with the hope it reveals some of the heart Dr. Lindberg put forward in his work accomplishing the Native Voices exhibition.

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Section Four

Memoirs, Resources, and Insights About Donald A.B. Lindberg M.D.

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Section Four: Memoirs, Resources, and Insights About Donald A.B. Lindberg M.D.

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Abstract: Section four provides additional insights into Donald A.B. Lindberg M.D.'s life, character, interests, and passions. It includes 20 memoirs, a few of his photographs, a Resource Guide, and an essay about the influence of his home library and leadership traits. Section four's 20 memoirs are brief, more colloquial, and sometimes personal. The memoirs discuss Dr. Lindberg's interactions with family, lifelong friends, biomedical informatics colleagues, and U.S. National Library of Medicine (NLM) peers. The Resource Guide, photos, and essay yield other insights and assist readers who wish to learn more about Dr. Lindberg.

Keywords: Donald A.B. Lindberg M.D., U.S. National Library of Medicine, memoirs, leadership

1. Introduction

Section four provides additional insights into Donald A.B. Lindberg M.D.'s life, character, interests, and passions. It includes 20 memoirs, a few of his photographs, a Resource Guide, and an essay about the influence of his home library and leadership traits.

Section four differs from the book's other sections, which describe Dr. Lindberg's contributions to biomedical informatics, worldwide access to scientific and health information, and outreach to the underserved. The tribute by NLM's Board of Regents on his retirement summarized Dr. Lindberg's professional impact as such: '(Dr. Lindberg) fundamentally (changed) the way biomedical knowledge and health information is collected, organized, and made available for public use – in small villages in Alaska and Mali as well as in laboratories of Nobel prizewinners. He has therefore empowered the public and transformed the conduct of research, the education of students, and the care of patients.'

In contrast, section four's 20 memoirs are brief, more conversational, and sometimes personal. The memoirs discuss Dr. Lindberg's interactions with family, lifelong friends, biomedical informatics colleagues, and U.S. National Library of Medicine (NLM) peers. The Resource Guide, photos, and essay yield additional insights and assists readers who wish to learn more about Dr. Lindberg.

While it is a challenge to portray the persona of a multi-dimensional person (who also was a disciplinary pioneer and a public figure), the contributions in this section enable readers to glimpse Dr. Lindberg's character and why he was highly respected. As

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Mark Twain wrote: 'there is a great deal of human nature in people' - and Dr. Lindberg was not an exception.

That said, the memoirs raise a few aspects of Dr. Lindberg's personality and character that might surprise people who did (and did not) have the opportunity to know him.

2. Memoirs - Family

The seven memoirs about Dr. Lindberg from family members include contributions from two sons, his grandson, two daughters-in-law, brother/sister-in-law, and brother. The memoirs focus on Dr. Lindberg as a father, grandfather, father-in-law, brother, brother-in-law, and family leader. Each memoir provides a snapshot of Dr. Lindberg's interactions that weave a tapestry of remembrances and insights.

For example, Jon Lindberg (Dr. Lindberg's son) writes about childhood fun on his family's Missouri farm, trips on horseback in several locations, and meeting a Nobel laureate [1]. Jon explains one of his father's gifts was the ability to communicate with persons from diverse backgrounds [1]. Jon explains Dr. Lindberg looked forward to conversations with the sanitation workers who collected the trash at the Lindberg's Maryland home as much as he enjoyed talking to the President of the United States [1].

Don Lindbergh (Dr. Lindberg's son) writes how his father's personality turned more demonstrative during a New York City visit [2]. After watching his father try to get routine assistance from New York City cab drivers, hotel desk workers, and waitresses, Don Lindbergh notes he became more self-assertive [2]. Don explains how his father persuaded the family's horses to gallop at their Missouri farm and notes Dr. Lindberg's nightly readings to his then-young sons [2].

Chris Lindberg (Dr. Lindberg's grandson) emphasizes his respect for the leadership Dr. Lindberg provided in the U.S.' cultural/professional transition to the digital age [3]. Chris also mentions the time he spent with Dr. Lindberg in a favorite family car, eating in a drive-in restaurant, and hearing him walk up the wooden stairs in his house after a long day at NLM [3].

Kelly McGee (Dr. Lindberg's daughter-in-law) introduces how Dr. Lindberg stayed informed and his enduring enthusiasm for the arts and culture [4]. McGee explains she began to understand Dr. Lindberg's professional influence on a trip to a biomedical informatics seminar at Woods Hole, MA. [4].

Amy Lindberg (Dr. Lindberg's daughter-in-law) recounts Dr. Lindberg's encouragement during a family boat journey in the eastern U.S. [5]. Amy explains how Dr. Lindberg enjoyed sharing family responsibilities. Amy details how she stood her ground, took charge, and contributed to the role as the craft's navigator [5].

Roy Musick M.D. and Linda Musick, Dr. Lindberg's brother and sister-in-law, note his influence on their professional life and hobbies. Dr. Musick suggests he would not have become a successful physician (who practiced in Northern California) if Dr. Lindberg had not persuaded him to try medical school [6]. Dr. Musick describes attending a memorable autopsy while still in medical school with Dr. Lindberg's enthusiastic coaching [6]. Similarly, Linda Musick explains how her interest in photography grew as a result of Dr. Lindberg's keenness and guidance [6]. She recalls Dr. Lindberg's emotional intensity during a visit to take photographs at Gettysburg, the site of a decisive battle during the U.S. Civil War [6].

Finally, in a narrative about growing up in Brooklyn, Charlie Lindberg (Dr. Lindberg's brother) writes about their childhood home, love of inexpensive cars, and assisting their father. He was an architect [7]. Charlie depicts Flatbush life and contrasts its affordability and degrees of freedom with contemporary urban society [7]. Charlie also compares how he and his brother spent one of the most difficult days in contemporary U.S. history - September 11, 2001 [7].

3. Memoirs - Life-long Friends

The four memoirs from life-long friends include contributions from Frederick L. Edelman M.D., Carl M. Pellman M.D., Tyler Abell J.D., and Charles Kalina MBA.

Dr. Edelman writes he probably met Dr. Lindberg in kindergarten at Brooklyn (NY) PS 197. Edelman notes how he, his wife, and the Lindbergs once received an appreciative salute for a lively conversation from a diner at a different restaurant table [8]! Edelman also introduced Dr. Lindberg to Carl Pellman during their senior year in high school [8].

Dr. Pellman, Dr. Lindberg's classmate at Amherst and at the College of Physicians and Surgeons at Columbia University, explains how they initially bonded from a mutual interest in experimental embryology [9]. Pellman adds he and Dr. Lindberg enjoyed the fun atmosphere created by Amherst professor Emile Shotte [9]. Pellman recalls that he and Dr. Lindberg continued working with Prof. Shotte to regenerate limbs in frogs and newts after college [9].

Abell, Dr. Lindberg's roommate at Amherst, provides insights into their colorful college life and undergraduate experiences. Abell suggests many of Dr. Lindberg's hobbies (including travel, boating, opera, reading, collecting books and music, photography, technology, and interest in science and the humanities) were formed by his 21st birthday [10]. Abell notes the friends Dr. Lindberg made at Amherst advanced his curiosity and wide range of interests early on and throughout his life [10].

Kalina, who was both Dr. Lindberg's childhood friend and an NLM colleague, notes how they worked together to prevent the deterioration of NLM's physical media, including optical discs and non-acid-free paper [11]. Kalina suggests Dr. Lindberg provided leadership in a then-vacuum of concern about the surprisingly short life span of paper-based products, which impacted the U.S. Congress's decision to require acid-free paper for future federal governmental use [11].

4. Memoirs - Biomedical Informatics Colleagues

Three long-time biomedical informatics colleagues, Randolph Miller M.D., Joyce Mitchell Ph.D., and Rashid Bashshur Ph.D., provide memoirs about Dr. Lindberg's contributions as a peer and a mentor.

Dr. Miller outlines Dr. Lindberg's contributions to the development of biomedical informatics as a discipline and Dr. Lindberg's impact on Miller's career [12]. Miller also stresses the significant personal and social contributions of Mary Lindberg (Dr. Lindberg's wife) to the field of biomedical informatics and NLM [12]. Miller, an Emeritus Professor at Vanderbilt University School of Medicine, is a key contributor to the book's first section and is one of the book's four co-editors [12].

Dr. Mitchell explains Dr. Lindberg's role as her career mentor, which began as a post-doctoral student through becoming the chair of the bioinformatics department at the University of Utah [13]. Mitchell also provides a *mise en scene* account of the sobering developments during the NLM Board of Regents meeting on September 11, 2001, and how the ensuing decisions to continue NLM's services reflected the Library's prominence and progress [13]. The aforementioned memoir from Charlie Lindberg reflects on the events he experienced across the Potomac River in Virginia on the same morning [13].

Dr. Bashshur describes how Dr. Lindberg and NLM supported Bashshur's work on the use of telemedicine in disaster preparedness/response, and to facilitate large-scale clinical trials [14]. Bashshur notes Dr. Lindberg and NLM also assisted Bashshur's efforts to write a book on the history of telemedicine [14]. Bashshur emphasizes Dr. Lindberg was a steady and reliable source of career support, guidance, and wisdom [14]. He suggests Dr. Lindberg's unique qualities and extraordinary influence helped Bashshur achieve his potential as a health care professional [14].

5. Memoirs - NLM Colleagues

Six memoirs are provided by persons with diverse backgrounds who worked with Dr. Lindberg at NLM: Dylan Rain Tree J.D.; Tom West Ph.D.; Janet Laylor B.A.; George Thoma Ph.D.; Steven Phillips M.D.; and Pat Carson. Their memoirs attest to the personal impact of the work environment and atmosphere at NLM that Dr. Lindberg cultivated.

Similar to Joyce Mitchell and Rashid Bashshur, the memoir from Dylan Rain Tree J.D. extols Dr. Lindberg as a mentor [15]. Akin to the memoir from Dr. Musick, Rain Tree notes how Dr. Lindberg persuaded him to become an attorney and devote his practice to Native American issues [15]. Rain Tree, who is a Native American, now practices law in Fresno, CA. He assisted in the development and expansion of the Native Voices exhibition at NLM.

Dr. Lindberg supported West's writing about the talents of dyslexic individuals and the importance of visual thinking in the history of medicine and science [16]. West notes his admiration of Dr. Lindberg's abilities to attract talented and creative people for his staff, NLM's Board of Regents, and NLM's diverse, inventive projects [16]. West recalls hearing Marc Andreessen, the founder of Netscape and the Silicon Valley venture-capital firm Andreessen Horowitz, speak at NLM on the day he distributed the initial software to access Mosiac, the world's first Internet browser [16].

Laylor adds her gratitude for Dr. Lindberg's and NLM's stellar support during her gender transition [17]. Laylor explains the tolerance exhibited to her was not unique and reflected an underlying forbearance at NLM for people, ideas, diversity, and innovation [17]. She suggests the latter was an essential element of Dr. Lindberg's successful 31-year tenure as NLM's Director [17].

Dr. Thoma applauds Dr. Lindberg's breath of vision and support for innovative projects at NLM, such as machine learning [18]. Thoma, who was the chief of NLM's Communications Engineering Branch (within the Lister Hill National Center for Biomedical Communications) for 34 years, underscores Dr. Lindberg's backing for the branch's document imaging and optical character recognition work to extract bibliographic data from scanned medical journal articles [18]. The latter initiative ensured MEDLINE, the leading international source of access to medical literature, could be kept up to date. Among other examples, Thoma notes Dr. Lindberg's

enthusiasm for *Turning the Pages*. This branch project facilitates the 'touching and turning' of a book's (scanned) pages and provides readers with a realistic look and feel of the original text [18]. Thoma additionally salutes Dr. Lindberg's efforts to create a family atmosphere for NLM's employees [18].

Dr. Phillips explains that he appreciated Dr. Lindberg's biomedical informatics contributions for several years before they met [19]. Phillips notes how he became involved at NLM as a member of the Board of Regents and later as the Deputy Director, and the director of NLM's Specialized Information Services Division [19]. Phillips adds an entertaining story about when he and Dr. Lindberg took off to cruise the Potomac River during an oppressive Washington D.C. heatwave [19].

Finally, Pat Carson (Dr. Lindberg's long-standing executive assistant) describes the behind-the-scenes work and effort needed to host many of NLM's social occasions and special visitors [20]. Carson amusingly recounts how she arranged Dr. and Mrs. Lindberg's Louis XIV/Marie Antoinette costumes for a well-received costume party that accompanied the opening of NLM's Frankenstein exhibition [20]. Carson underscores that despite a constant array of activities at NLM, it was fun to work with and support Dr. Lindberg (as well as Mary Lindberg) [20].

6. Other Contributions in Section Four

In addition to the memoirs in section four, an essay by the current author explains the influence of Dr. Lindberg's home library. It discusses two of his leadership traits: the cultivation of discovery and project development in educational administration and the need for leaders to determine and act in the greater public interest [21]. The chapter suggests the latter two traits defined Dr. Lindberg's NLM leadership [21].

A Resource Guide is provided to help readers learn more about Dr. Lindberg and NLM's activities during his 31-year tenure as director [22]. Among other things, the Resource Guide contains some tributes written after Dr. Lindberg's death, accolades received when Dr. Lindberg's retired from the U.S. National Library of Medicine, resources about Dr. Lindberg's career and contributions, manuscripts authored by Dr. Lindberg, and links to NLM annual reports written during Dr. Lindberg's helm [22].

Section four adds several photographs selected by Mary Lindberg, illustrating Dr. Lindberg's artistic/creative side [23]. A collection of Dr. Lindberg's photos, including some of the images selected herein, surrounded the walls of NLM's Lindberg room (where the Board of Regents and senior staff members met) for many years.

Overall, the contributions in section four furnish informal snapshots into Dr. Lindberg's character, interests, and contributions. They yield wide-ranging insights into Dr. Lindberg's persona and interactions with family, friends, and colleagues. Section four also provides a 'tell me more' educational resource about Dr. Lindberg, which was a service he championed for health professionals and the public throughout his career. The aggregate contributions provide a collage of Dr. Lindberg's family and professional life, leadership skills, and inspiring contributions.

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Memories of My Father

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Keywords. Donald A.B. Lindberg M.D., Lindberg family history

1. The Farm

In the 1960s, my father (Donald A.B. Lindberg M.D.) bought a 130-acre farm north of the mid-western town, Columbia, MO. It was on this farm that my brothers and I learned to swim, fish, ride horses, ice skate, shoot guns, and ultimately help dad finish a cabin by the lake. We came of age there. I learned skills from my father that have stuck with me and shaped who I am.

Fishing, ice skating, swimming, and guns were all cool until Dad got us horses. He spent time learning about horses and discovered a common fault when getting children into horses was to buy a Shetland Pony, which is bred for their small size but not necessarily for their disposition. I would learn many years later that my dad's decisions were well researched, and the results, in this case, were three wonderful, gentle, well-mannered horses from the Swedish island of Gotland. Mom's horse was a combination of Gotland and Thoroughbred. Dad's horse was a Tennessee walker.

We would go on family rides exploring our farm. Hot summer's day rides would always end in a run and jump off the dock into the cool lake water. There were cold spots in the lake where spring water rushed from beneath and finding them was always rewarding. It was off this dock that I discovered the art of pan-fishing. This involved a pan, a chunk of bread, and the skill to scoop up a fish as it came to the water's surface. I got good at this, and while on my own in my cowboy boots with spurs and sometimes nothing else, my dad would take Time-Life quality photos.

2. Becoming a Cowboy

When I was seven, I began working with my first horse, a pure-bred Tennessee Walker named Suzy. My dad had bought a mare, we had her bred, and I experienced the anticipation and wonder for the day my little horse would arrive. I cared and handled her for a couple of years until she was strong enough to saddle and ride. She was a very powerful and fast horse and, at times more than I could handle. I got bucked off often, and convinced, by my dad, to get back on until we trained (broke) that horse. My brother Chris helped out more than a time or two while I was healing. He would come in from a ride with my dad and say, 'man, that horse is turbocharged.'

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My father took our family on many extraordinary horse-riding adventures. Starting in Missouri and continuing to Colorado, these trips were epic. Dad had his Mercury Marquis retrofitted for airbags and a special reinforced trailer hitch attached directly to the car's frame. This enabled us to pull a horse trailer with a four-door family car. We drove that rig from Columbia, MO., over Independence Pass and the continental divide into Aspen, CO. During our journey, we would come to a ranch at night, and dad would unload the horses into someone's corral that he had arranged. The horses would rest, get water and food, and we would head off in the morning.

3. Traveling

The trips to Colorado, Oklahoma, and California made a big impression on me. Dad knew I loved riding as well as traveling. He had taken us to The Devil's Fork Dude-Ranch in Colorado, riding with Don King M.D. at King Ranch outside Aspen, as well as a well-organized ride on the Choctaw Nation Trail in the Ouachita Mountains of Oklahoma.

On the Indian Nations trail ride, I saw an amazing side of my dad that I had not witnessed before. I saw him learn some aspects of horse care in Colorado. When he later applied one lesson as an aid to some fellow riders, I realized that knowing something and conveying it to someone else were completely different things.

There were riders from many different states on the trail ride in Oklahoma, and some of their horses were not accustomed to drinking clear, fresh, snow meltwater. The result was the horse would refuse to drink. My dad showed some very concerned ridders that you could lead a horse to water, but sometimes the way to make him drink was to put some dirt in clean, clear water. So, from an ultimate communicator, I learned it's in the way the message is delivered….

4. Influences

Over the years, I would discover there were many interesting sides to my dad and so many proficiencies. We were all so fortunate to have learned from his example. There is no question that the things he taught me and the opportunities he and my mom made available shaped the way I am and the way I navigate the world. Photography, carpentry, powerboating, sailing, the art of putting on a successful social event are examples of skills he taught me. I have used a combination of these skills to become successful at various stages in my life. It is profound to think that my dad's influence on me was so strong. I continue to learn from his examples and lessons.

Growing up exposed to such good examples and diverse opportunities have made me realize my brothers and I had a fantastic childhood. We came of age under the guidance and influence of both our parents. It was said to me, by a good friend, that if he did not know my dad, he would have to conclude that none of my stories and experiences could have occurred or been true.

For example, I could not possibly have gone on a business trip to California with my dad to meet Ray Kroc (founder of McDonald's) at his horse ranch, select my horse and ride with him all afternoon in the mountains - where actual condors lived and hunted. I could not have spent a week with Ansel Adams, Bret Weston, Paul Caponigro, and

other famous photographers attending a private course on Ansel's Carmel coast property. I most certainly could not have sailed in a trapeze position on a racing sailboat in the famous Viking town of Friesland, in the northern province of the Netherlands. Being taken by my dad to the dinner table of Dr. Albert Sabin (developer of the oral polio vaccine) at the Cosmos Club in Washington, D.C., for an introduction was a true honor. To watch my dad communicate with persons of intellect while possessing the facility to talk with the men that collected our trash was amazing. Watching dad build a darkroom out of empty space in our basement and later during dinner discuss the conversations he had with the President of the United States also was memorable.

In closing, the best story I have is when Donald A.B. Lindberg came to Washington State University to speak to the Neuroscience Department, where I hold a Research Assistant Position. Dr. Lindberg was very well received.

While these stories may seem boastful and outlandish, they are genuine examples of some of the gems that I have as memories of adventures with my dad. He grew up in Brooklyn, NY. Attended PS-197, Polytechnic Preparatory Country Day School, Amherst College, on to Columbia University College of Physicians and Surgeons - and the rest is history. I knew and will remember him as a visionary medical doctor, computer scientist, humanitarian but most importantly, a loving, caring, all-knowing, and consistent father.

Learning from My Dad: Donald A.B. Lindberg M.D.

Donald A.B. LINDBERGH, IT Cybersecurity Specialist, Indianapolis, IN. U.S.A.[1]

1. Farm

I read an article by Betsy Humphreys mentioning a remembrance by Diane McKenzie that my dad "relished his role as the crowing rooster" during a 'Comin' Round the Mountain' game at a 1986 Medical Library Association chapter meeting in Jackson Hole, WY. "He did it with gusto, McKenzie recalled. He earned my eternal support with his willingness to be silly with the rest of us" [1].

My dad (Donald A.B. Lindberg M.D.) really did a good cow moo as well.

However, his best 'pre-verbal' exclamation was when Jon, Chris, and I were very young and on horseback with him at our farm in Missouri, a fantastic 130-acre location.

My brothers and I prepared by getting well seated in the saddle and a firm hold on the reins, egging him on and knowing what was to come. Then, my dad would let out a blood curding scream like a Comanche, and the horses would take off at full tilt, and we raced across the fields.

He kept a shearling-lined leather rifle scabbard on his saddle at all times. If we encountered hunters on the property, he would approach them and make sure they saw the rifle. Then, dad demanded to know what the hell they were doing on his land. It was like something out of 'Gunsmoke,' a TV show we all loved.

We had a cabin on the farm, and we helped dad build bunk beds for each of us. The cabin had a heater named 'Shingebiss' after the Ojibwa Native American story we begged him to read to us repeatedly [2].

2. Reading

When my brothers and I were very young, dad read to us nightly regularly. We had a separate, dedicated library, so the available options were many. These included traditional stories from Greek mythology; Daedalus and Icarus was a popular, recurring choice [3]. My personal favorite came from a Japanese mythology collection, a tale of the Rokurobuki, guaranteed to scare and delight every time [4].

I'm still trying to reconnect with that book from my dad's remaining vast collection.

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3. New York City

Dad took me to New York when I was 11 or 12. I was super excited.

After arriving in a rental car leaving LaGuardia Airport, a cab behind us honks for us to get a move on. Dad instantly gets out of the car and approaches the taxi behind us, causing the cab driver to react in terror and quickly lock all his doors. Dad pounds on the driver side window - BOOM BOOM BOOM…. 'DON'T HONK YOUR HORN AT ME.' Then, he calmly gets back in our car, puts it into gear, and eventually pulls forward. When he damn well pleases….

Once in the city, we often found ourselves in cabs. These were thrilling and somewhat terrifying experiences for me as I could not believe how fast they drove and how narrowly they seemed to escape collisions. After giving one driver a tip, the cabbie took dad for a tourist and asked if he would tip 20 percent. Dad, who grew up in Brooklyn, proceeded to lay into the cab driver about how New York's cabbies were the worst in the world and whether he would like to be reported to get his medallion removed for reckless driving. Dad suggested he would be happy to take back the tip, being barely deserved.

Waiting at the hotel desk once, with nobody paying attention or coming to attend, dad pounded on the desk. BOOM BOOM BOOM. HEY! LOOK ALIVE! A stunned staff immediately hopped to attention.

Taking me to Chock Full O' Nuts in the morning to get breakfast, the restaurant was at capacity and crazy busy and loud. Sitting at the counter, the drill was to be ready when the counter clerk finally came by to take your order. I hesitated, so dad ordered, and the clerk said she would return for mine. It soon became clear you only got one shot, and she was not planning a comeback. This time dad did not take charge but counseled *I needed* to get her attention.

I flagged her down. HEY! I'm READY TO ORDER!

4. Work

My brothers and I were rounded up for chores around the house including cutting down trees for firewood. When we asked about allowances, dad came up with a pay scale per job. Twenty-five cents to sweep out the garage and for other chores. However, he made it clear there would not be a payout every week without a job being done.

5. Some of Dad's Enduring Messages

Don't take (expletive deleted) from anybody, don't wait around for somebody to pay attention to you, don't wait around for somebody to ask you to do something to help.

Later in life, I lamented about losing a job and pondered how to explain it in an interview. In a letter, dad said I should clarify that I had been a dedicated, loyal employee who tirelessly supported a broken old computer system for years, *which was a perfect encapsulation*.

Reading his letter, a friend of mine remarked: 'you've got a good dad.'

I agreed.

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Icon

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Icon is a glamorous term awarded to a few people for any number of achievements. The meaning of the term, like many things, has a different meaning now than it did or will in the future.

Sadly, my generation's (under 30) perceived icon is personified by someone whose money is primary - and all the other niceties to be an icon begin and end with a monetary value. Accomplishment is measured by nothing other than the dollar.

In contrast, Donald A.B. Lindberg M.D. (my grandfather) was a more classic and genuine icon. In high school, he wrote: 'Naturally there is always something better for which to reach; but if the ambitious person does not stop for a while to enjoy what he has in the moment, he never has a chance to actually enjoy himself.'

Indeed, the latter was something my grandfather mastered. He was true to himself and his interests, and he achieved them. It's so fortunate that my grandfather's ambitions were in the best interests of the world and the people in it because he was unstoppable. From the time he was born until his death, he was the embodiment of accomplishment. He was a collegiate scholar, cowboy, pilot, picture-perfect family man, and an internationally recognized physician.

Moreover, my grandfather nurtured a generational transition from pre-to-post information technology for scientists, health care providers, and the public. To backup, while my generation has known and depended on information technology, our experience contrasts with the pioneers who conceived and developed computing in its diverse socio-cultural and professional forms. The transition was not easy for people (especially those born in the pre-digital age) who did not have the mental acuity to embrace a gestalt switch.

In contrast, my grandfather not only made the change - he embraced and led it. He spent his life integrating information technology and medicine. His contributions to biomedical informatics were as unmatched as the splendid leadership of the U.S. National Library of Medicine under his guidance, which is addressed elsewhere in this book.

More personally, as I get older and gain a more front-row seat to life and its process, I realize the more simple and basic memories of my grandfather are the ones I cherish the most. These include: sitting in the back of an open Ford Escort; eating at Sonic (our favorite); teaching me how to swim in the backyard; or his footsteps up the stairs after a day at the office. These recollections are accompanied by the years I spent visiting the National Library of Medicine and the family of friends I made there.

These are among the things that stand out when I think about my grandfather.

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He was a man who truly cared not just about those in his immediate proximity but persons all over the world. He often said: 'To live life to the fullest also means to make a real contribution to society.' My grandfather's contributions to the world and humanity will be remembered forever and represent both undeniable acts of greatness and living life to the fullest.

Donald A.B. Lindberg: Uomo Universal

Kelly McGEE[1]
Pullman, WA. U.S.A.

I am admiring a photo Dr. Lindberg took years ago of the wet bricks of the patio at his home in Missouri. Don and Mary built the house, and he laid each of the individual bricks. You can feel the chill in the air and see the sun's rays melt the snow. The photograph connects your senses and feelings as he experienced them.

Don loved all forms of art and incorporated them into his scientific work and initiatives. Don could design a house and pioneer medical computing, each with confidence and success. He could accomplish anything to which he committed time and energy, and he never stopped learning. Indeed, my father-in-law influenced me to achieve, persevere, and never be afraid of new experiences.

When visiting the Lindbergs' home in Maryland, I looked forward to walking the halls and enjoying Don's photographs. He documented his admiration for his family, travel, and everyday objects with a unique perspective.

Yet, the most comforting part of a visit was knowing you would find Don sitting in his chair reading. There was an endless stack of newspapers, books, journals, magazines, and maps. He was interested in many subjects and he continued to study and effortlessly share his knowledge - all within the warmth of the family room.

Later, Don graciously took my family on cultural outings throughout the greater Washington area. We gratefully saw Renoir's 'Luncheon of the Boating Party,' heard Mozart's 'The Marriage of Figaro,' and dined at a social club in the presence of Nobel Prize winners.

Overall, Don was a person of his time. He stayed up to date with current events as well as trends in literature and arts. He displayed expertise in cultural history and politics. Don's example prompted me to take time every morning and evening to read and stretch my scope of knowledge and insight. He demonstrated the more you read, more events seemed connected, if not universal.

My fondest memory was attending a biomedical informatics course with Don and his family at Woods Hole, Massachusetts. While we were there, I began to understand Don's commitment better to delivering health information to providers, patients, and the public, as well as train the next generation of health informatics specialists. He lived to share knowledge with others.

During one Woods Hole day, Don joined his family on a squid collection boat after class. It was fascinating to watch him communicate with the captain and other locals on the crew. Following the boat ride, Don immersed himself in the seaside community by talking to patrons at Captain Kidd, a local tavern.

Don's competence and knowledge often made him one with whomever he conversed. Also, just by being with him at Woods Hole, I was introduced to the

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importance of healthcare technology, the steps to building a wooden sailboat, and how to value others.

In July 2012, my family received a collection of Don's photographs, 'Where Is Fancy Bred.' The title was intriguing and sparked my curiosity to study each photo and read his passages. The majority of the pictures depicted his love for water, the most vital element in the universe. The images reminded me of these verses in the Tao Te Ching:

> His heart is kind like water that benefits all.
> His words are sincere like the constant flow of water
> His governing is natural without desire which is like the softness of water that penetrates through hard rock.

As I perused the book, I realized that Don saw unlimited potential in all living things, which influenced his life purpose. He was a gentleman with a firm handle on understanding himself and the world around him.

Don, thank you for being a Captain in the vast waters of science, literature, history, art and for believing in me.

Don Lindberg: Helping Others Thrive

Amy LINDBERG[1]
La Grande, OR.

Donald A.B. Lindberg M.D.'s ability to find another's strengths was terrific. When he saw them, he let you progress.

Dr. Lindberg (my father-in-law, whom I called 'papa') liked to see people succeed no matter the size of the accomplishment.

Here is a brief account of what occurred on a boat trip to Florida when he discovered I had a good sense of direction and became the family's vessel navigator.

Before a planned family boat trip from Virginia to Florida, Papa sent a set of waterway charts so I would have an understanding of where and how we were going. I was used to reading road maps but not charts. He let me highlight the channels we would follow. While he was not sure the latter was necessary, I convinced him it would help. He later agreed that, indeed, it *was* helpful at a glance to see where on the chart we were located.

On the first night of the trip, we needed to find an intended destination-marina. It was hard to read the shoreline from our position in the Chesapeake Bay and a fast-approaching dusk. Papa perceived we needed to be further south; I thought a little more to the north. Our GPS showed the course of where we had been, which in this case was a sloppy circle.

I said the spot with the most and brightest lights would likely be the marina. So, we headed that way and fortunately found it.

The next day we entered the harbor in Norfolk, VA. The first Inter Coastal Waterway marker set us off to the south. Once there, the options for the best channel to navigate were not obvious. Papa (aka 'the Captain') wanted to start over. Since I was sure I read the markers correctly, I responded we should stay the course.

However, the Captain proclaimed "start over." So, we redid some steps - and ended back at the same spot.

"Okay," he said, "you were right." Looking at the chart and finding our channel, we continued - and so it remained for the rest of the trip. From then on, I was the navigator and Papa, the Captain.

The story suggests Dr. Lindberg did not need to shoulder all of the limelight. He was very encouraging of others to find their sweet spot and make the best of their efforts. Ultimately, he wanted us to discover what we do well and thrive.

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Don Lindberg's Diverse Influence: An Interview with Roy Musick Jr. M.D. and Linda Musick

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Keywords. Donald A.B. Lindberg M.D., Roy Musick Jr. M.D., medical education, photography, Lindberg family history

'Don Lindberg convinced me that I should go to medical school,' Roy Musick M.D. said at the outset of an interview in fall 2020.

Dr. Musick described an all-night chat that occurred more than a half-century ago. As Donald A.B. Lindberg M.D. and Musick discussed his professional future, he mentioned he wanted to pursue a Ph.D. in psychology. Dr. Lindberg cheerfully responded; '*Oh no*… you *must* go into medicine.' (Dr. Lindberg was Musick's brother-in-law).

Recalling the conversation vividly, Musick noted at the time he self-questioned his academic ability to handle medical school.

Dr. Lindberg quickly responded, 'You do not have to be smart to go to medical school...You just have to keep your head down (persevere)… they hand you a degree and ... then, you can do what you want.'

Although the task took several years, Musick said he eventually learned that: 'Don was right…When I looked up, I was an M.D. and gained so many professional pathways and opportunities.'

Dr. Musick laughed about how a conversation that seemed so casual at the time turned out to be transformative. He became an internist with a specialty in gastroenterology and enjoyed a 46-year career practicing medicine, mostly in the northern suburbs of San Francisco.

Dr. Musick also recalled a memorable visit to a New York City hospital during Dr. Lindberg's early years as a pathologist. Dr. Lindberg invited Musick to watch an autopsy in progress, which Don believed to be exceptionally instructive.

'The autopsy was gruesome, and the room was without air conditioning during one of the hottest, humid days during a New York summer,' Dr. Musick said. However, Musick recalled Dr. Lindberg did not seem to notice. Instead, he enjoyed explaining to Musick, then a medical novice, what they were seeing and learning.

'Although Don perceived I was getting weak in the knees, he kept encouraging me to keep standing, which somehow I managed to do,' Dr. Musick said. Musick added Dr. Lindberg was a 'born mentor' and his willingness to assist never abated.

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Although he worked with many distinguished health care providers during his career, Dr. Musick said Dr. Lindberg was: 'the only great man I have ever known.'

Linda Musick (Roy's wife) experienced a different side of Dr. Lindberg's personality and character during their 50+-year friendship. Ms. Musick, a former English teacher, liked to go on photoshoots with Dr. Lindberg during family trips.

Ms. Musick explained she partially learned how to be a photographer because of friendly competition with Don. She recalled they would visit a site, take a different approach to producing photos, and later, compare and critique their harvest of images.

'Don taught me how to load black and white film and how to develop it,' Musick said. The first time she developed film was in the darkroom at the Lindberg's house in Columbia, MO.

'Don liked to photograph nature, which sometimes brought out his spiritual side,' Ms. Musick said. She keenly recalled Don's photographs of the Gettysburg PA wheat field where Gen. Robert E. Lee's Confederate army fired its first shot on July 1, 1863.

Musick explained she and Don challenged each other to visually depict different aspects of the wheat field more than 120 years after the penultimate U.S. Civil War battle. An estimated 7,058 soldiers died, 33,264 troops were wounded, and 10,790 were missing after three days of combat that began on the Gettysburg wheat field. The post-clash triage in the town and battlefields of Gettysburg lasted for several months and partially inspired Abraham Lincoln's Gettysburg address. Human remains are still found on site from time to time.

A few minutes after Dr. Lindberg began to take photos of the Gettysburg wheat field, Ms. Musick explained, he suddenly turned to her and said: '*can you feel them*' (referring to the soldiers who fought, died, and were wounded there). 'To both of us, the soldiers seemed to have a real presence as we walked in their footsteps more than a century later.'

Dr. Lindberg's emotive reaction to walking through the battlefield was repeated at other Civil War locations they visited later, including Antietam.

Besides his professional demeanor, 'Don had a spiritual side that surfaced especially when he was photographing nature in historic locations,' Ms. Musick said. 'I was privileged to be there sometimes…'

Ms. Musick suggested Dr. Lindberg's spiritual dimension also was evidenced by his commitment to and involvement in the Native Voices exhibition towards the end of his NLM career. Ms. Musick, who attended Native Voices' opening @ NLM, said the exhibition conveyed Dr. Lindberg's interest in Native medicine, how and why it works, and its interface with modern medicine.

Ms. Musick explained that Dr. Lindberg appreciated the contributions of providers who coupled Western medicine with traditional healing practices. She noted he sought to create a platform (with NIH's authority) to educate others about the diverse individual, familial, and socio-cultural elements that underlay health and illness.

Ms. Musick added Dr. Lindberg understood that healing occasionally requires more than clinical adherence to evidence-based protocols. 'Sometimes, healing requires inspiring the human spirit,' she said.

Growing Up with My Brother, Doctor Don: Interview with Charles Lindberg

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Keywords. Donald A.B. Lindberg M.D., Lindberg family history, Brooklyn

In a spring 2021 interview, Charlie Lindberg remembered his Brooklyn-based childhood and the life-long assistance of his older brother, Donald A.B. Lindberg M.D.

As Charlie called him throughout his adult life, 'Dr. Don' helped Charlie when he a teenager by lending him an ID. Charlie explained in the 1940s-50s, identity cards did not include someone's photo. 'Dr. Don's ID said light brown hair, blue eyes, thin, and about 6.5 feet tall, which described him as well as me.'

'So when he (Dr. Don) was 14, I was 12.'

Using Dr. Don's ID on occasion, Charlie was more eligible to work and perhaps buy a beer. (Charlie explained the legal drinking age in New York City at the time was 18).

Charlie's teen odd jobs included parking cars at Lundy's seafood restaurant, shining shoes near a Kings Highway bus/subway stop, and diving for coins at the Sheepshead Bay waterfront. Charlie joked how much further money went during his formative years: 'If I shined shoes for a nickel and made 40 cents, I was a millionaire.' He explained a movie was 12 cents, candy and some soft drinks at the theater were just two cents.

Charlie added if he shined shoes on Wednesday, Friday, and Saturday or dived for coins in the summer, he could clear 75 cents a day. Besides going to the movies, Charlie said he could bike to Ebbets Field (to watch the Brooklyn Dodgers baseball team), pay 60 cents for a bleacher seat, spend 10 cents for popcorn - 'and still have change.'

"It was safe and free to park your bike near the ballpark. I never experienced vandalism or a stolen bike.'

With a sense of nostalgia coupled with amusement, Charlie underscored that during his childhood. some urban roads were unpaved, and Brooklyn seemed to be a big village of residents who sometimes befriended social innocence.

'I know it sounds strange to kids today - but living was much easier back then.'

To provide an example of Dr. Don's escapades and illustrate how urban environments and American culture have changed in 75 years, Charlie noted one of Dr. Don's pastimes was his active participation in the rifle club at Poly Prep Country Day School.

For outdoor practice, Charlie explained Dr. Don would carry a rifle *almost as is*, take the 22 bus in Brooklyn to the BMT (train), which took him to the School's practice facility. Don took this routine journey throughout high school sans problems. 'Can you imagine anyone pulling this off today?' Charlie asked.

Charlie added Dr. Don could practice indoors in the basement of the Lindberg's Brooklyn brownstone home. Charlie noted Brooklyn's mid-20th century brownstone

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homes - often built less than a century earlier - featured large, long, accessible basements. Until the second decade of the 20th century, the sizeable cellars served as the place for a family's horses and wagons. Charlie continued that some brownstone basements were so well constructed and insulated that the Lindberg's neighbors never noticed Don's rifle range activities.

During this era, Charlie explained he and his brother frequently helped their father, an architect. For example, Charlie and Dr. Don measured some distances within garages that were undergoing an overhaul. Charlie explained garage renovations boosted business for architects because the use of garages shifted in the 20th century from horse stables to electric cars, to internal combustion cars and trucks, to other family or work conversions.

He said their father (Harry Bror Lindberg) also architecturally designed bottling plants for Pepsi, Coca-Cola, and a local dairy. Harry Lindberg additionally designed the first color television studio in Brooklyn, the renovation of the Lunt-Fontanne Theater on Broadway, and the home of American philanthropist Mary Duke Biddle. Charlie noted the Biddle house featured a then-rare bowling alley in the basement.

Skipping ahead to the era when the Lindberg brothers were in their early 20s, Charlie noted automobiles were so inexpensive that both he and Don could purchase one for $25-$60. When U.S. gas prices spiked two generations later, Charlie recalled Dr. Don once paid $80 to simultaneously fill three tanks for himself, Charlie, and Mary Lindberg. As he paid the bill, Don remarked to Charlie: 'do you realize we could *buy* a car for less money only 40 years ago!'

Charlie said Dr. Don's favorite automobile was a 1929 Chandler 8 that he purchased for $60. A framed ad for a Chandler sits in Don's home library. Don could climb in with a slight head turn to the right when he was at his desk.

Moving to September 11, 2001, Charlie was pitching in Fairfax. VA. during a Virginia senior league softball game at the time a passenger jet deliberately flew into the U.S. Pentagon. Fairfax is geographically adjacent to the Pentagon. As a U.S. military veteran and a dedicated softball pitcher, the experience left a deep impression. Charlie moved to his current residence in the western U.S. state of Oregon precisely a year later.

At the moment Charlie left the pitching mound during the Pentagon attack, Dr. Don was hosting the U.S. National Library of Medicine's (NLM) Board of Regents meeting in nearby Bethesda. Some of the developments at NLM on 9/11 are described in Joyce Mitchell's memoir within the current book [1].

Charlie worked for RCA and IBM for many years and at times lived in the same area as Don and Mary Lindberg. Throughout the past 50 years, Charlie has spent significant time with members of the Lindberg family with whom he remains happily in touch.

'Dr. Don was a great, gifted man. However, to me, he will always be my helpful older brother…'

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Donald A.B. Lindberg: A Lifelong Friend

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Keywords. Donald A.B. Lindberg M.D., Fredric L. Edelman M.D.

Don Lindberg and I grew up together in Brooklyn, NY. We probably first met in Kindergarten, PS 197.

Another memoir in the current book explains that I introduced Don to Carl M. Pellman M.D., and they became lifelong friends. Dr. Pellman was Don's colleague at Amherst and our peer at the Columbia University College of Physicians and Surgeons in the 1950s.

Despite a continental divide (my wife Emily and I moved to Los Angeles years ago), Don and I kept in contact. Emily and I saw Don and Mary whenever the opportunity arose.

Regarding our meetings, one of my fondest memories occurred just several years ago. Mary and Don, Emily, and I had dinner near Los Angeles International Airport at a hotel where Don and Mary stayed before a flight to Australia.

After dinner, another guest who dined alone unexpectedly came over to our table. He exclaimed that although he ate solo, his meal was memorable because he could hear the four of us chat enthusiastically about plentiful topics and frequently laugh at ourselves and others. Until that moment, I was not aware that our friendship was so rich and gratifying that it could be recognized as rewarding by others. Yet, such was Emily and my relationship with Mary and Don.

As with many friends, you never know the scope of their accomplishments until you read obituaries or attend a memorial service. The latter also is my case with Don Lindberg, whom I admired for eight decades.

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Don Lindberg: A Seven-Decade Friendship

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Keywords. Donald A.B. Lindberg, M.D., Amherst College, Oscar E. Schotte

I met Don Lindberg in the 1950s through Frederic Edelman, a neurosurgeon currently of Encino, California, whose family and mine are close. When Fred discovered his two good friends would attend Amherst, he got us together, and a lifelong friendship began.

At Amherst, Don and I shared an interest in biology, in which we both majored. In our junior year, we developed a special, mutual interest in experimental embryology. At that time, I began to appreciate Don's quiet and creative genius as we studied for exams together long into the night and worked in the laboratory of Amherst Professor Oscar Emile Shotte on the regeneration of limbs in amphibia. Don concentrated on developing frogs, and I focused on newts.

In springtime, armed with nets, Don and I (and our class) joined Prof. Shotte to search local caves and ponds for experimental subjects. Following each spring hunt, we celebrated with a keg of beer and local Polish spreadable sausage with rye bread.

We spent idyllic afternoons drinking wine in Prof. Shotte's office, talking about experimental biology, politics, and women, subjects to which we were all attentive. It was so meaningful and fun to work with Shotte that we continued during the summers following college graduation and between our first and second years of medical school at the College of Physicians and Surgeons (P and S), Columbia University.

After completing medical school, Don did not take a customary year of internship in medicine or surgery. Instead, Don persuaded P and S's Department of Pathology to design an internship just for him. While it was highly unusual to create an internship tailored to one individual, the decision attests to Don's extraordinary abilities.

Indeed, Don was remarkably attached to Columbia University for many reasons. After all, it was there (in the Pediatric Outpatient Clinic) where he met his wife-to-be, Mary. The rumor was when the time was right; he would formally request her hand in marriage. The latter was a good decision.

While I lost contact with Don for some years after his wedding, it was a pleasure to renew our friendship when he and Mary returned to the eastern U.S. in the 1980s. During his tenure as director of the National Library of Medicine, Don revitalized the library and made a magnificent contribution to medicine and science.

Finally, it is an honor to write about Don and a friendship that spanned seven decades.

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At Amherst and Afterwards: Interview with Tyler Abell About Don Lindberg

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Keywords: Donald A. B. Lindberg M.D., Amherst College, Oscar E. Schotte

The Orange Blossom Group formed during Don Lindberg's sophomore year - when he lived with several roommates in a three-bedroom suite at Amherst College. Orange Blossom was the Group's Sunday beverage of choice - a concoction of gin, vermouth, and orange juice. (Dr. Lindberg eventually preferred bourbon).

In a summer 2020 interview, Tyler Abell described the Orange Blossom Group's life-long friendship and added a few insider tales. For example, some Orange Blossom members were airplane pilots. Don took flying lessons and received a pilot's license in college. If an Orange Blossom Group member flew on Sunday, he was a temporary teetotaler.

Dr. Lindberg stood out within the Group because: 'Don loved science …. and he looked younger than most of us,' Abell said. After graduating from Amherst, Abell became an attorney and was the Chief of Protocol for the U.S. during the Johnson administration. The Lindbergs and Abells lived near each other in suburban Maryland after Don arrived as the National Library of Medicine's director in 1984.

Abell noted how much the then-teenage Lindberg enjoyed working with Amherst embryologist Dr. Oscar Schotte. Abell explained it was somewhat unusual for students to become close to Amherst professors in their underclassmen years. After all, Amherst's faculty included poet Robert Frost.

Yet, Don (who once scored a perfect 100 on a challenging course exam) regarded Schotte as a mentor almost immediately. Outside of family members, Schotte remained one of Dr. Lindberg's enduring influences, Abell explained.

Recalling a few exploits from a more innocent era, Abell said Don once arrived a half-day late for a Washington year-end visit and forgot to bring a tuxedo needed to attend holiday events.

Although most of the Orange Blossom Group enjoyed music, Don *again* stood out because he loved opera. The latter was problematic because his enthusiasm was unrequited - and there was only one place to play records inside the Group's suite. Even worse, some of Don's opera records and their packaging were irregularly sized and could scratch other recordings if placed on top or next to them.

Yet before quarrels emerged, a clever roommate built a case where 78s and LPs could slide into a groove space, and the individual records and their cases did not touch each other. 'Even the opera and Benny Goodman records fit,' Abell exclaimed. (Some recordings of the Goodman band were distributed in cases that were as difficult to store as operas).

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So, although Don's roommates may not have been enamored with *Don Giovanni,* diva-like disputes and disruptions never erupted.

More seriously, Abell explained each member of the Orange Blossom Group was challenged by the possibility of military service in the Korean War. Like most male college students in the early-1950s, each Group member possessed a draft card they received at age 18. 'Initially, we worried if we would even be able to go to college and later whether we would be able to graduate,' Abell said.

While the Korean War provided a constant reminder about everyone's vulnerability, Abell noted that living with uncertainty helped bring the Group together and intensified how college students perceived their broader social responsibilities. In addition to Abell and Lindberg, the subsequent careers of other Group members featured public service and charitable work.

While separated by geography, the Orange Blossom Group members remained concerned about each other's health and welfare long after they graduated from Amherst. Abell said Dr. Lindberg took the time to assist Group members to find physicians for themselves or family members. Abell also noted when one of the Group members became seriously ill in late middle age, others (including Dr. Lindberg) rallied successfully to help him find better medical care and remain upbeat.

Regarding Dr. Lindberg's growth and interests, Abell suggested many of Don's hobbies (including travel, boating, opera, reading, collecting books and music, photography, technology, and interest in science and the humanities) were formed by his 21st birthday.

Abell added Don's curiosity about Washington's inner workings might have been influenced by occasional visits with Drew Pearson, a legendary Washington insider columnist who was Abell's stepfather. In later years, Dr. Lindberg's exposure to Washington protocols was boosted by Bess Abell, Tyler's wife and First Lady Lady Bird Johnson's social secretary. The late Ms. Abell later ran Bess Abell Enterprises, a well-connected Washington public relations firm.

Of course, it helped that Mary Lindberg (Don's wife) grew up in Washington and was reasonably comfortable with the city's cognoscenti and social norms, Abell explained.

Meanwhile, Dr. Lindberg's ability to lead was an accumulation of experiences, interests, counsel, access, energy, intelligence, and perseverance, Abell said. While the Orange Blossom Group may not have Don's life and career, its members encouraged his curiosity and wide range of interests early on and throughout his life.

Don Lindberg: Best Friend and Colleague

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Classically and appropriately, festschrifts tend to remember an individual's professional achievements. Those were Don's many. But my memories include Don as a person and as my best friend since high school days, a sentiment I trust was mutually returned.

The high point of our high school experience was a 1949-50 senior year, joint ownership of 1929 Chandler sedan - purchased for $60. Don was the designated driver, with his driver's license mailed for $1, not from a *Cracker Jack* box, but the State of Missouri. Those were calmer Truman days, with a better feeling of trust in society. In retrospect, it must have been those of our permissive parents, reflecting their faith in our budding teen competence,

In addition to providing mobility around hometown Brooklyn, the Chandler survived a round trip to northern Virginia (to visit a school friend who transferred to a local boarding school in his senior year) - with only a detached muffler in front of Washington National Airport. We walked across the tarmac to a hanger where we borrowed some tools to repair it - another memory of action of faith that could scarcely be repeated some seventy years later.

Then, we grew up.

We resold the Chandler for what we paid and, well-prepared at Poly Prep Country Day School, dispersed to college, medical school, and graduate science training - with a break in the Army for me. I made a quick trip from my then-rocket scientist duties to attend Don's marriage in Washington to his darling Mary in 1957. Later, we enjoyed a vacation as joint crew on a rented motorboat, anchoring on the Hudson River in the shadow of West Point and pumping out a rudder mounting leak on Long Island's Great South Bay.

Don joined me as my best man at my wedding in Chicago in 1962. I was cheered on that occasion by Mary accompanied by their first newborn, Don Jr.

By that time, my interests as a consultant broadened, and I became a community agency, state health systems planner for Rhode Island, residing in Boston. Don was increasingly recognized as an authority in medical informatics and was on the University of Missouri's medical faculty.

A commonality of health expertise made it possible for us to keep in touch, notwithstanding the distance involved. I visited Don's department in Missouri and shared developments in the art of health planning - and enjoyed diving into Columbia's swimming quarry. Boston's popularity as a scientific conference site provided periodic opportunities for Don to visit Boston. We enjoyed dining at Pier Four in Boston Harbor.

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As an inveterate photographer, Don would document the visits, a record I continue to cherish.

After federal funding revisions in the 1980s, health planning became the responsibility of state health departments. I no longer perceived the state of Rhode Island took advantage of my capabilities and interests. So, in 1986, I joined (hopefully to its reward) the National Library of Medicine (NLM) for the rest of my professional career.

At the time, Don was concerned about preserving the original scientific research that was available on NLM's multi-media platforms. Don knew that as electronic and other access to selected information improved, preserving the growing corpus of biomedical research (stored electronically and on NLM's shelves) became increasingly problematic. Although media preservation concerns were widespread, the topic received limited and isolated attention with little remedial collaboration.

More specifically, electronic media faced the prospects of obsolescence and the possible deterioration of materials, such as optical discs. Paper (science's original mass medium) simultaneously needed preservation from increased decline caused by age (in some cases) and a 20th-century abandonment (by publishers of biomedical books and journals and many others) of more expensive permanent, acid-free paper. Overall, NLM's information storage expertise and mission as the nation's medical library provided a significant venue to initiate an innovative preservation program.

With Don's continued interest and encouragement, NLM vigorously pursued preservation activities for several years. NLM formed an active permanent paper task force of paper manufacturers, publishers, and information users, and pursued other, specific preservation interests with Abbey publications, a leading journal for preservation interests.

NLM additionally testified at pertinent Congressional committees. NLM supported the U.S. Senate and House of Representatives passage of PL 101-423 in September 1990, signed by President George Bush into law in October 1990, which required the use of permanent, acid-free paper in federal publications. With live voice and guitar renditions of 'Songs of Paper' that was part of a hearing, a national task force of eight publishers, three major paper manufacturers, and 22 concerned institutional representatives led broad paper and other media preservation reforms in October 1991.

In 1993 Don's seconding appointment as director of the High-Performance Committee on Communications and Information Technology (HPCCIT) in the President's Office of Science Technology Policy attested his national reputation. I accompanied him as Executive Secretary. Developing policy direction was not the only task of the office, which also served as an incubator for entrepreneurial talent within the then-nascent U.S. digital revolution. After two formative years, Don returned to the full-time helm of NLM. I soon resumed my NLM tasks, and the Library remained a source of personnel talent for the HPCCIT in subsequent assignments.

Don continued his NLM directorship for another two decades. I retired in 1997 to devote more time to developing some family real estate property in Boston; but I continued to reside in Maryland. This made it possible to enjoy Don's company and pool and continue, with Mary, to crew on the "L' bon Femme" on the Potomac and the Chesapeake, all 32 feet and 220 horsepower of it.

Today I enjoy a quiet, well-earned retirement, which is more the reason to treasure one's twilight years. Yet, it is tragic many retirement years were taken from Don due to his accidental passing. My life was richer by knowing him and following his inspiring example as a leader, mentor, and friend. While Don may be gone, his memory continues to thrive deep within me.

Remembering Don Lindberg: Two Letters

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1. Introduction

The memoirs below are excerpted from two letters I wrote to Donald A.B. Lindberg
M.D. on his retirement in 2015 and Mary Lindberg, Don's wife, after his death in 2019.
The letters cover aspects of Don's character, career, and contributions to biomedical
informatics. The letters add a tribute to Mary Lindberg, whose support nurtured the
careers of many researchers and practitioners in biomedical informatics.

2. Letter to Don and Mary Lindberg when Dr. Lindberg retired as NLM's director in March 2015

Dear Don and Mary,

Thank you for serving so graciously as the First Family (like George and Martha) of
American biomedical informatics - from the field's infancy to its current maturity. Your
examples and initiatives created a community that cares about people and each other.
That Mary has shared in and contributed to meetings and activities in our field says much
about you and your gifts of leadership and compassion.

A majority of faculty members in U.S. academic biomedical informatics units,
including me, owe their careers to the training programs, institutional initiatives, and
sponsored research grants that Don initiated during his tenure at the National Library of
Medicine (NLM). Building Don's exemplary leadership as its first President, the
American Medical Informatics Association (AMIA) grew to become the foremost
organization promoting the field. Beginning with Don's formative term as its President,
AMIA served as a respected national forum and advocate for informatics policies and
priorities.

Don's passion in recent years for telling the story of Native Americans, both in
general and concerning health care, exemplifies how he initiates diverse projects with a
unique commitment to excellence. In reading Kent Nerburn's book, *Neither Wolf Nor
Dog*, my wife Linda and I at times saw aspects of Don in the way Nerburn objectively
and authentically conveys the perspective of Native Americans [1].

At other places in the book, we also perceived Don as Dan, the wise, older Native
American philosopher, at all times taking a broader view of the field of biomedical

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informatics - knowing instinctively where it has been, where it is now, and where it should go.

In the book, Dan's words explain why Don has been among the longest-serving directors within the National Institutes of Health in recent times:

> 'There are leaders, mand there are rulers. We Indians are used to leaders. When our leaders don't lead, we walk away from them. When they lead well, we stay with them.
>
> White people never understand this. Your system makes people rulers by law, even if they are not leaders. … How can a calendar tell us how long a person is a leader? That's crazy. A leader is a leader as long as the people believe in him and as long as he is the best person to lead us. You can only lead as long as people will follow.
>
> That's why Sitting Bull was a leader. He was needed by the people and the people followed him. He was brave. He was smart. He knew how to fight when he had to. And he understood what the white man [i.e., government] was all about. People saw that he could not be tricked by the white man, so they followed.'

Otherwise, Linda and I deeply treasure the occasions when you devoted the time to get to know our family. When you visited Pittsburgh in the 1980s, Mary prepped our young daughters for the prescient photos that Don took of them, which accurately forecasted their adult visages. Mary spent a wonderful time with Linda's mother that I think each valued highly over the ensuing years. Similarly, it was a profound honor to be entrusted with the care of Mary's aunt in Pittsburgh despite difficult circumstances. One wonders if the Creator dealth with in poetic justice when Mary later delivered compassionate hospice care to Linda's aunt.

We also enjoyed walks with you through the streets of Europe - especially in Zurich and Paris - and memorable dinners in restaurants as part of the Health on the Net (HON) Foundation activities started by our friend, Jean-Raoul Scherrer.

Thank you so much for being who you are. To paraphrase Star Trek's Spock, we hope you will continue to live long and prosper in retirement.

3. Letter to Mary Lindberg after Dr. Lindberg's death in August 2019

Dear Mary,

With deep sadness and a profound sense of esteem, Linda and I learned of Don's passing last month. As Yoda of the Star Wars movies said on momentous occasions, "There has been a great disturbance in the Force." We extend our condolences to you and your family.

No individual influenced my career in biomedical informatics as much as Don. Through his pioneering leadership of the National Library of Medicine (NLM) during three decades, the NLM's sponsorship of grants and training programs that influenced hundreds of institutions and thousands of individuals, and Don's leadership of the American Medical Informatics Association (AMIA) during its formative stage, he created a flourishing environment for our field (and my career).

Of equal or greater importance, Don was an exceptionally caring individual whose concern for others humanized the biomedical informatics field since its inception. We experienced this directly through the warm friendship you, Don, Linda, and I shared, which began with your visit to Pittsburgh in the 1980s. Under Don's guidance and

Dr. Lindberg (left) and Dr. Miller (right) in front of the Louvre in Paris in October 2009

with you often co-hosting, NLM's Biomedical Informatics, Library and Data Science/Biomedical Library and Informatics Review Committee's study sections met not just to review grant proposals but also to share group dinners and camaraderie at various sites in Bethesda and DC. The sense of shared friendship characterized the leadership style that Don encouraged in our field.

Don's love for his family also was evident in how, despite a busy and demanding job, he was always up to date on the activities of his children and grandchildren. I remember how you and Don hosted meals and swimming parties at your house for the initial groups of NLM trainees, which fostered lasting friendships among the participants. Don took a deep interest in professional activities and the lives and families of his acquaintances.

Don was a remarkable person who mastered every venue of a diverse set of interests. He also did so in a manner that inspired others. Don was exceedingly well-read and had a deep appreciation of history. He shared his opinions with an impressive mustering of facts and logic to support what he said. His photography skills brought delight and long-lasting memories to many. Among other examples, Don enjoyed the opera and was a consummate expert in the intricacies of the composers, works, and performances.

Although the world has suffered a great loss in Don's passing, it is evident through his life and accomplishments he left us in a far better place. Our thoughts and prayers have been with you since we learned of Don's death.

Reference

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Donald A.B. Lindberg M.D. - My Mentor

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1. Introduction

This memoir focuses on a few examples of Donald A.B. Lindberg M.D.'s influence on my career in biomedical informatics. He was always accessible to me from the point of my postdoctoral fellowship starting in 1976 until I became the Chair, Board of Regents of the National Library of Medicine (NLM) in 2009, and NLM's representative on the Council of Councils for the National Institutes of Health (NIH) from 2011-2014. I retired shortly after this and was amazed that Dr. Lindberg continued to serve NLM until 2015.

I briefly describe some of the most memorable examples in this memoir. I start at the University of Missouri - Columbia (MU), move to my sabbatical at NLM, and work at the University of Utah. Dr. Lindberg and I became close colleagues over the years, but I will always consider him my primary career mentor.

2. The University of Missouri-Columbia (MU)

Dr. Lindberg recruited me to be a postdoctoral fellow at the University of Missouri-Columbia in 1976, and he changed my whole career. Dr. Lindberg supervised some predoctoral and postdoctoral fellowships at MU as part of a health care technology training grant program. I had just finished my Ph.D. at the University of Wisconsin-Madison, focusing on population genetics and a graduate minor in probability and statistics with programming skills.

Specifically, I was looking in Columbia, MO., for a postdoc or a job. I married the last year of my doctoral work, and my husband was the chair of the mathematics department at Stephens College in Columbia. He wanted to be near his children as they grew up. I agreed I would look for a job in Columbia first, then Kansas City and St. Louis.

Dr. Lindberg interviewed me for the postdoc position and said: 'you have the perfect background to be part of this new field called Medical Information Sciences.' I had never heard of it but decided that I would take a leap of faith and spend two years giving it a try.

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Those two years were a fantastic, whirlwind learning experience and different from my Ph.D. work. Dr. Lindberg would become my primary mentor for my informatics career, spanning the next thirty-five years.

In the mid-1970s, the Medical Information Sciences Program at MU revolved around a center grant from the U.S. National Center for Health Services Research (NCHSR). MU was the U.S. designated Center for Health Care Technology (HCTC). We collaborated with the MU School of Medicine, College of Engineering (industrial engineering and computer engineering), College of Nursing, College of Health Sciences, School of Journalism, and School of Information Sciences. It was a stimulating, multidisciplinary environment.

The program's goal was to identify and assess new technologies that would change health care environments. We explored online information retrieval in fields such as law with LEXIS (legal information services), as well as searching on MEDLINE. This led to explorations of controlled vocabularies such as Medical Subject Headings (MeSH) and Systematized Nomenclature of Medicine - Clinical Terms (SNOMED).

We evaluated pharmacy information systems to determine if they decreased drug interactions. We assessed radiology and pathology information systems for the timeliness of their results and their impact on providers workflow. We also evaluated workflow in clinics to search for improvements in time and efficiencies and assessed the capability of early telemedicine systems to provide services to rural populations. We developed and evaluated patient communication services.

The engineers worked to create a 'computer in a briefcase,' which was a prototype for the microcomputer industry. The rapidly emerging CT scan technology warranted a comprehensive literature review. We were, in fact, collecting the literature of health services research as it focused on technology and developing a system on a microcomputer to store and retrieve the data.

We evaluated health care software with Rutgers University (Casimir Kulikowski Ph.D.) and medical experts alongside our technology focus. This led to a dual-track of relational databases compared to hierarchical databases for storage and retrieval of patient data and expert systems to assist with diagnosing and treating patients based upon such data. We began with rheumatic diseases (Gordon Sharp M.D.), branched out into dermatology (Philip Anderson M.D.), coagulation (Montgomery Gaston M.D.), and genetics (Sandra Davenport M.D.).

The NCHSR/HCTC with related grants and projects was a rich learning environment for a postdoctoral fellow. Above and beyond the content of the specific technology projects, it was instrumental for me to learn about grant site visits. Grant visitors included NLM, the U.S. National Institutes of Health (NIH), the U.S. Center for Disease Controls and Prevention (CDC), the U.S. Department of Defense (DOD), and other U.S. federal health-related agencies. I wrote my first grant, my initial scientific papers, gave professional presentations and technical demonstrations, and learned the skills vital for success in all academic fields.

My dilemma was how to get a faculty position in the MU School of Medicine to continue to be part of the exciting field and work with Dr. Lindberg and his team. At the time in the U.S., there was only one department of Medical Informatics (this name later evolved to biomedical informatics), which was located at the University of Utah. MU's School of Medicine did not have such an entity. At the time, Dr. Lindberg was the Director of the Medical Information Sciences Group, a research group that reported to the Dean of MU's School of Medicine. But the faculty all had their primary appointments in traditional departments.

After some deliberation, I decided to apply for another postdoctoral position in clinical medical genetics. My Ph.D. in genetics had become clinically relevant to an emerging focus in MU's Department of Child Health (traditionally called Pediatrics). I took a detour and was accepted at the University of California-San Francisco for a two-year fellowship. I focused on clinical genetics but researched the development of a clinical information system to assist in retrieving patients with clusters of symptoms that might form new syndromes. After developing this on a University mainframe, I transferred it to a North Star microcomputer. The latter was a boon to the genetics research community and broke new ground using microcomputers in the clinical domain.

The happy ending was my acceptance of an offer of an assistant professor tenure-track position in the Department of Child Health at MU. I devoted half of my time to research collaboration with Dr. Lindberg and the Medical Information Sciences Group. The position became the foundation of my ensuing academic career with a focus on informatics and domain knowledge in medical genetics.

MU's School of Medicine provided unending opportunities to expand my horizons as a faculty member. I spent 25 years at MU, and the time flew by.

When Dr. Lindberg became NLM's Director in 1984, he nominated me to be the Director of the Medical Information Sciences Group. The Dean of the School of Medicine appointed me to be the Director of the renamed Medical Informatics Group. Our work expanded to assist with teaching medical and nursing students how to search the literature to help with patient care.

We partnered with the J. Otto Lottes Health Sciences Library (Dean Schmidt MLS) to become a grant recipient from NLM for Integrated Advanced Information Management Systems (IAIMS), which involved strategic planning for the entire MU Health Sciences Center (HSC) schools and hospitals/clinics. I became Chief Information Officer of the MU-HSC and Associate Dean of the School of Medicine to achieve the goals of our strategic plans. Among many things, this involved replacing the majority of the systems in the hospitals and clinics to overcome the date problem associated with the new millennium (Y2K) and simultaneously provided a foundation for an electronic medical record system. The latter experience might be likened to shoving a camel through the eye of a needle.

After MU-HSC successfully migrated its systems, I was ready to return to academic research and leave the CIO administrative role to a successor. As part of this transition, Dr. Lindberg suggested that I had earned a sabbatical and offered one to me at NLM.

3. Sabbatical at NLM

I arrived for my sabbatical at NLM in 2001 just as two momentous events occurred; the September 11, 2001 attack on the U.S. and the completion of the draft of the Human Genome Sequence. Incidentally, the 9/11 attack occurred during NLM's Board of Regents meeting. I will discuss both experiences and their impact on my work.

The events on 9/11 provided memories many Americans vividly recall, and I witnessed the day through a unique vantage point at NLM's BOR. In addition to distinguished scientists and clinicians from a broad spectrum of the U.S.'s research and library communities, NLM's BOR consists of prominent members from the national agencies involved in informatics activities. In addition to the Directors of the two other U.S. national libraries (the Library of Congress and the National Agricultural Library), ex-officio members include the U.S. Surgeon General, the U.S. Medical Surgeons

General of the Army, Navy, and Army Medical Command, the Undersecretary for the U.S. Veterans Health Administration, the President of the Uniformed Services University of the Health Sciences, and the Director for Biological Sciences of the National Science Foundation. I list all of them because the first speaker of the day was NIH's Director.

While NIH's Director was speaking, the first plane struck the World Trade Center, and the next hit the Pentagon. Before the third plane hit, all of the beepers in the room started calling these representatives to return to their duties post haste to save lives and the country. The U.S. President immediately decided to vacate the federal government, which included NIH. NIH's Director then asked NIH to close down all of their computers and evacuate.

Yet, Dr. Lindberg responded NLM's computational/information resources were designed to help the U.S. in times of disasters and emergencies, and NLM computers were not going to shut down. Dr. Lindberg knew NLM's information resources were instrumental in assisting with the chemicals released and created by the downed buildings and to search for critical literature to help care for the wounded. NLM's genomic resources also came into play to identify body parts found by matching DNA samples.

The day's events demonstrated how NLM was foundational to almost every aspect of medicine and public health and suggested the centrality of the Library's work. Along with NLM's staff, Dr. Lindberg had put the Library in an indispensable educational position in American medicine, health care, and society.

What a momentous time to start a sabbatical!

Moreover, 2001 marked the completion of the draft of the human genome sequence - the Human Genome Project's (HGP) goal. Although I arrived in August 2001 to stay for a year, I continued to work on my project for the next seven years.

Dr. Lindberg challenged me to develop a system that would help him explain the significance of the results of the HGP to legislators and the public. While he believed it was crucial for the federal funding for the HGP to continue unabated, the results and benefits were not clearly stated in terms of their relevance to human health. The challenge combined my expertise in genetics and bioinformatics with consumer health informatics.

The project became the Genetics Home Reference, a system that remains at NLM - having recently merged into MedlinePlus, NLM's resource for consumer health information (https://medlineplus.gov/genetics/).

The original team included me, Alexa McCray, Ph.D., her staff, Sandra Davenport, M.D., and Rob Logan, Ph.D. We incorporated three design principles as we developed Genetics Home Reference that demonstrated their utility for the next 20 years.

Principle one was to make the site easy for the public to access with understandable content. Principle two was to interrelate and integrate existing resources extending from consumer health resources to clinical and scientific resources. Principle three was to create an informatics-based knowledge resource that would enhance the project's sustainability [1]. From the start, all content was edited for accuracy by medical geneticists who were members of the American College of Medical Genetics. The content also was revised to include lay language whenever possible. From its start in 2004, Genetics Home Reference was used heavily by the public, educators, librarians, and health care professionals, including medical geneticists. It was gratifying to create a resource for the world and to see it endure.

Of course, several more opportunities were offered to me by Dr. Lindberg while I was on my sabbatical. I became involved in the NLM informatics course at the Marine Biological Institute in Woods Hole, MA., eventually becoming its Director. I became more involved with the International Medical Informatics Association (IMIA), and several European Union (EU) projects. I became more engaged with the American College of Medical Informatics (ACMI) and later was elected to be the President of ACMI.

But all good things like sabbaticals eventually must end. I returned to the MU as a professor in the newly created Department of Health Informatics and Administration. Shortly afterward, I was recruited to be chair of the Department of Medical Informatics at the University of Utah.

4. University of Utah

I spent the last ten years of my career with the joy of being chair of the world's first department of medical informatics, building on the legacy of Homer Warner M.D. and Reed Gardner Ph.D. Although there is much that I could share about this time, suffice it to say that many great projects were accomplished, and many people were involved. Dr. Lindberg continued to serve as my mentor as well as a colleague. He visited and gave talks on multiple occasions, including several days of vacation in the national parks. Photo 1 is a photo of Don and Mary Lindberg on the Great Salt Lake marina during one of those trips.

Photo 1. Don and Mary Lindberg on the Great Salt Lake marina.

5. Conclusion

Dr. Lindberg changed my life and career trajectory by recruiting me to be a postdoctoral fellow at MU. He became my primary mentor as I progressed in the field that became known as Biomedical Informatics. With his guidance, I progressed from being a complete novice to an internationally recognized biomedical informatics professional. My ultimate accomplishment was being appointed a NLM Board of Regents member, eventually serving as its chair. I also was selected to be NLM's representative on the NIH Council of Councils, which helped advise NIH's Director, Francis Collins M.D., Ph.D. Dr. Lindberg was always available, insightful, interested, listened, gave his best advice, and followed up. He was a remarkable mentor, and my gratitude persists.

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Don Lindberg's Wisdom and Influence: A Personal Perspective

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I had the good fortune to meet Donald and Mary Lindberg during the first national conference of the American Telemedicine Association in Atlanta in 1994. I remember the encounter vividly because it was a special event to commemorate and honor the tragic passing of their son Chris, an early advocate of telemedicine in that era I had met the year before. That encounter was brief, and little did I realize or think that it would be followed several years later by an eventful, rich, and rewarding experience that had a profound impact on my professional life.

In 2001, Don Lindberg invited me to attend a special telemedicine symposium in Bethesda, organized by the National Library of Medicine (NLM) to highlight the research findings on telemedicine funded by the NLM from 1994 to 2000. At lunch in NLM's cafeteria, Don asked about my impressions of the symposium and what issues remain to be addressed through further research. Toward the end of our discussion, he asked if I would consider spending a year or more at NLM as a resident scholar to pursue my research interests unencumbered by other work demands. Don said the Library would expect me to acknowledge NLM in anything I wrote while in residence. However, NLM would not restrict editorial initiatives or make other stipulations or requirements. Don added he might ask my views about important topics about telemedicine.

I thought the overture was unusually generous. It was an academician's dream and the best offer I have ever received. Candidly, my inner-most thoughts at the time were: 'this great man sees something in me that I am not sure I possess.'

Nonetheless, it was difficult for me to move my family to D.C. and, we did not act on the generous proposal at that time. Some five years later, I wrote to inquire whether the offer was viable and if I could work from Ann Arbor, Michigan. Don agreed and said I should work with Mike Ackerman on the arrangements. Mike turned out to be a walking encyclopedia on NLM's bureaucracy. With his guidance, efficiency, and kindness, we became life-long friends.

During that year, I wrote a few policy pieces that Don was interested in pursuing, particularly the use of telemedicine in disaster preparedness/response, and in facilitating large-scale clinical trials. I also started to collect materials for a History of Telemedicine book, which was later sponsored by the NLM and published in 2009 [1]. I returned to the fountainhead several times. Don consistently rewarded me with support for several national symposia and the publication of a series of journal articles on the empirical evidence that undergirds telemedicine research.

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Although we met during the latter part of my career, Don had a profound effect on helping me achieve my ultimate dreams without asking for much in return other than to deliver on my promise. Indeed he was a giant of our time, a scholar of the highest order, a critical thinker, and a true pioneer in the development of telemedicine. Don was unique in many ways, perfectionist yet unpretentious, with varied interests but none superficially, and a precious dry sense of humor. Don also possessed the rare trait of seeing both the forest and the trees, each in proper perspective.

Looking back at the years gone by and the many people I met during my professional career, I can appreciate Don's unique qualities and his extraordinary influence in helping me achieve my potential. He was a steady and reliable source of support, guidance, and wisdom. He was never hesitant to express his point of view or point out how best to frame issues and text, yet he was disarming in his genuine courtesy and kindness. At times, he helped re-orient my thinking in a few words or hints. He was direct, thoughtful, and to the point, qualities that I always admired. Don could almost complete some of my sentences before I uttered them, almost as if he knew what I was would say.

He was honest and proper to a fault. I learned that if Don liked any of my ideas, they probably were reasonable. To my relief and sense of pride and humility, his comments were constructive and perceptive. He was a professor's professor. I truly appreciated his pedagogic shorthand in explaining complex things.

Returning to our interactions, Don provided advice on some health issues; he was genuinely interested in my health and wellbeing. In addition, it intrigued Don that I was educated at the American University of Beirut (AUB). Calvin Plimpton, AUB's President (1984-1987) and a friend of Don's, invited him to join the AUB faculty. From time to time, Don would test me on an esoteric topic. He asked me once where Argentina geographically was located in relation to the U.S. I missed that Argentina was located East - not just South - of the U.S. Although I flunked the quiz, Don smiled and said: 'you are alright.'

I will always miss Don's dry smile, his sense of purpose and destiny, and his ability to cut through clouds of uncertainties to arrive at the truth. I feel blessed for his presence in part of my life. Overall, Don was one of the most admirable people I have ever known or met. His loss leaves a deep void in my life.

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Dr. Lindberg's Mentorship

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1. Introduction

I first met Dr. Lindberg in June 2009 while a summer intern at the National Library of Medicine, National Institutes of Health (NLM). At the time, NLM was developing a new library exhibition focused on Native American, Alaska Native, and Native Hawaiian health. At the end of my internship, Dr. Lindberg invited me to continue working at NLM to assist in the exhibit's development. I agreed and thus began my work and mentorship with Dr. Lindberg.

2. I Became an Attorney Because of His Encouragement

Dr. Lindberg was a formative influence in my life. While I am now a practicing attorney, I might not be one if it was not for Dr. Lindberg's encouragement.

During a private conversation in Dr. Lindberg's office, he once asked me what I wanted to do in life. I answered somewhat timidly that I wanted to help other Native Americans in a moment of honest emotional vulnerability. He listened and took a moment to think. He responded thoughtfully and said it seemed Native Americans could use 'good legal representation.' Dr. Lindberg immediately shared what he observed first-hand during his visits to 'Indian County' [1]. He said it looked like some tribes were still being taken advantage of and could excel with better lawyers.

His response heartened me. It solidified an aim - becoming an attorney - that had not become a determined goal. From that conversation, I began the process of applying to law school.

The latter episode is an example of Dr. Lindberg's generosity and impact. He took a significant amount of time to talk to me during my tenure at the NLM from 2009-2015. Dr. Lindberg was an active advisor who exemplified what a mentor should be. He would listen, ask several personal questions, and give sincere feedback rooted in his wisdom.

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3. Personal Time Spent with Dr. Lindberg

Several times, Dr. Lindberg invited me to his house for dinner, sometimes right after a late night at work. I enjoyed a healthy, delicious meal prepared by Mrs. Lindberg and spent time with Dr. Lindberg talking and learning.

Our dinner conversations would begin with a pre-meal drink in the living room, engaging in small talk. We would talk about the exhibit, current politics, and so on. When dinner was ready, we proceeded to the dining room, where Mrs. Lindberg prepared the dinner table. We continued our conversations. Often, Dr. Lindberg asked me more personal questions such as my opinions on U.S. policy towards Native American tribes to more random questions such as where I purchased my clothes.

During the entire time, Dr. Lindberg displayed his dry wit, curiosity, and listening skills. When dinner ended, I left feeling he cared about me. At first, the latter was sort of uncomfortable since it was rare (in my experience) for a mentor to care so much for a mentee. Amusingly, I began to think of Dr. Lindberg as my father on the East Coast of the U.S. while my birth father and family were on the West Coast. All along, I knew I could receive valuable insight and advice from Dr. Lindberg on anything.

4. Reflections After Leaving NLM

The more I heard and observed his relationships with others, the more I realized Dr. Lindberg displayed the same care and concern for many others that he showed to me. He cared about many NLM employees, and this attitude created an emotional bond that fostered a sense of loyalty and admiration.

I met numerous people while working at the NLM who had worked with Dr. Lindberg for decades. Their relationship with Dr. Lindberg was like my own; an ongoing rapport boosted their professional lives.

After I left the NLM in 2015 to attend law school, I kept in touch with Dr. Lindberg. After I passed the California bar exam to become a licensed attorney, I informed Dr. Lindberg of the news. His response included: 'You're off and running now.' It was a great response, typical of his style. He was usually direct and concise while being personable. His answer provided me a feeling of satisfaction in my accomplishment and confidence in the world of possibilities ahead of me.

I am grateful for the time I spent with Dr. Lindberg, and I will continue to remember and imagine the advice he would provide me today. Dr. Lindberg's legacy endures in so many people and institutions where he devoted his time, care, and efforts. He was a wonderful person, and I was fortunate to have him as a mentor for several years.

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Personal Memories of Donald A.B. Lindberg M.D., Visual Thinker and Medical Visionary

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Keywords. Donald A.B. Lindberg M.D., visual thinking, computer graphics technology, dyslexia, U.S. National Library of Medicine

1. Introduction

From the late 1980s until his retirement in 2015, I was privileged to observe the forward-thinking and astonishing depth, range, and liveliness of the National Library of Medicine (NLM) under the direction of Donald A. B. Lindberg M.D.

As an outsider, I observed from my point of view as an ordinary library researcher. I mainly utilized NLM's History of Medicine collections for information about innovative scientists like Michael Faraday and medical pioneers such as Dr. Harvey Cushing. Initially, I used the old paper index catalog cards, microfilm, and the early NLM mainframe computer information systems to research and prepare the manuscript for my first book, *In the Mind's Eye*, published in spring 1991 [1].

I first met Dr. Lindberg at a gathering after a lecture in NLM's Lister Hill Building. He asked about my work. I explained that my research focus concerned the talents of dyslexic individuals - together with visual thinking in the history of medicine and science. I was surprised to discover that Dr. Lindberg also was interested in these topics.

I later learned that these interests were partly a reflection of his personal history. Don's father was an architect. Don was trained in a highly visual specialty, pathology, and some family members were dyslexic. As is often the case, this kind of personal history helps some to understand and appreciate the puzzling mixed strengths and weaknesses that accompany these life patterns.

I also was fascinated that Don's interests included then-rapidly developing computer graphic technologies as well as the hidden talents of dyslexics (who often see things differently) to innovate and sometimes make scientific discoveries before conventionally trained experts in some fields. Over time, I began to appreciate that Dr. Lindberg had a remarkable ability to see where things were going and attract highly talented and creative people for his staff, NLM's Board of Regents, and the Library's diverse, inventive projects.

Over the years, Dr. Lindberg assumed leadership positions in several major areas - archiving massive amounts of genetic code information (within the National Center for Biomedical Information), providing research information in clinicaltrials.gov, and even leading a federal government-wide effort - the High-Performance Computing and

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Communications Program (HPCC). He once remarked to me how difficult it was to deal with 500 HPCC emails a day.

Dr. Lindberg's interest in visual thinking and dyslexia was evidenced when he asked me to be the after-dinner speaker at a meeting of NLM's Board of Regents [2]. He accorded me the honor of describing the ideas I developed during my research and writing. I began my BOR speech with these words:

"My talk this evening is about a return to visual thinking. My subtitle 'new technologies, old talents and reversed expectations,' encapsulates my main thesis - that as we begin to use the newest technologies in really powerful ways (which we have hardly begun), we will begin to tap into some of our oldest and most "primitive" neurological (visual spatial) talents. In so doing, we will begin to see ourselves and our world with very different eyes – leading, in time, to fundamentally different attitudes towards education and concepts of intelligence, as well as the skills and talents that are considered to be the most valuable. . . ."

2. Advanced Applications

At NLM in the late 1980s and early 1990s, I witnessed the rapid changes in computer systems happening worldwide. Dr. Lindberg seemed to be simultaneously interested in the newest technologies, and at the same time, he respected the insights and sophisticated knowledge of early researchers and traditional cultures.

For example, one morning I chanced to attend another lecture in NLM's Lister Hill Building. The speaker was a sleepy young computer programmer and software engineer. He had been up all night, as he said, releasing to the World Wide Web thousands of copies of a new computer program he and a coworker designed - called a 'browser.'

As it turned out, it was 'Mosaic,' the first web browser of its kind. The young speaker was Marc Andreessen, then working at the National Center for Supercomputing Applications at the University of Illinois. Later, he became famous in the computer world for Netscape and the Silicon Valley venture-capital firm Andreessen Horowitz. Of course, these initiatives helped enable access to the Internet. They revolutionized mass communication - and I was privileged to see the very first day - primarily because of NLM and its forward-thinking director.

3. Thinking Like Einstein on the Hokule'a

During his career, Dr. Lindberg became known as a significant innovator in using computers for healthcare research and practice. Under his direction, NLM pioneered broad access to medical information with Medline and PubMed. But Don also promoted a deeper understanding of less well-known groups with programs such as 'Women in Medicine' and 'Native Voices.'

'Native Voices' exemplified how Dr. Lindberg promoted the investigation of the traditional forms of medicine, widely ignored previously. In later years, I was thrilled to see that NLM played a significant role in a visit to Washington, D.C., during the round-the-world journey of the traditional Polynesian canoe, the Hokule'a - a double-hulled sailing canoe that enabled the early Polynesian peoples to travel among the islands of the broad Pacific Ocean.

I was delighted to see Dr. Lindberg's interest in this area. Previously, I followed the renewed practice of traditional navigation methods and the significant influence of its rebirth in generating pride and reviving traditional Polynesian culture. Of course, the early traditional navigators used the stars and other natural signs. However, traditional navigators also taught themselves to feel long-distance ocean swells to maintain a heading - and how the absence of 'shadow' in these swells could indicate the presence of an island, out of sight, over the horizon. I wrote about these insights in my second book, Thinking Like Einstein [3]. Indeed, the intended full title for the second book was to have been: Thinking Like Einstein on the Hokule'a.

Dr. Lindberg was well aware of how traditional cultures used visual abilities in highly sophisticated ways - with a minimum of technology and a sophisticated integration of profoundly understood natural forces. I was amazed and delighted when the Hokule'a tied up for several days at the Washington Canoe Club on the Potomac River in the middle of Washington, DC. Nainoa Thompson, the chief traditional navigator, gave a major talk at NLM about traditional navigation methods.

Like Andreessen, NLM provided a stage for an important person (who was not well known outside of Polynesia) to provide fresh perspectives and ideas. In a way, both talks were so typical of Dr. Lindberg's NLM.

Moreover, I enjoyed several conversations with Nainoa at the Canoe Club, where he confirmed his special visual-spatial skills in traditional navigation probably were linked to his dyslexia. We talked about our everyday dyslexia experiences and the dyslexia of some family members. It all seemed to support the theory from Harvard neurologist and dyslexia researcher Norman Geschwind, M.D., who suggested the visual-spatial abilities often seen among dyslexics yielded an array of socio-cultural benefits [4].

4. Dr. Lindberg's Prescient Leadership

Over time, I beheld how prescient Dr. Lindberg was in providing leadership during an era of enormous change and rapid progress. Don used his broad interests and deep understanding of the potential of computer systems in the service of medical knowledge and practice.

One especially forward-looking conference was organized in mid-February 2000. At Dr. Lindberg's direction. The 'Visualization Research Agenda Meeting - The Impact of Visualization Technologies - Using Vision to Think' considered how: 'new visualization technologies are giving us new ways of seeing and understanding: bringing diverse worlds together, transforming the nature of education and work, redefining what we understand is talent and intelligence.' The meeting focused on the implications of visualization technology for education and professional training, as well as how to build an appropriate research program.

It was a small but diverse meeting with only 22 attendees. NLM's participants included Dr. Lindberg, Alexa McCray, Michael Ackerman, and Steve Phillips. Other attendees represented: five institutes at the U.S. National Institutes of Health; two from the Smithsonian Institution; three from computer graphics organizations; and six persons with knowledge and experience regarding dyslexia, giftedness, and the brain's evolution.

Among those in attendance was Alvy Ray Smith, Ph.D., a strong advocate for the power of computer graphics in many spheres. Dr. Smith was one of the two founders of the Pixar Animation Studios in Emeryville, CA. Dr. Smith was a member of NLM's Board of Regents and helped with the Visible Human Project and other related programs.

Other attendees included William J. Dreyer, Ph.D., California Institute of Technology, who provided a striking example of the power of dyslexic visual thinking in science and medicine. Dr. Dreyer had been a classic dyslexic when young; his reading, spelling, and arithmetic assessment scores were substandard. But having performed well on other tests, Dr. Dreyer went on to study biology - and gradually realized he could tell his professors what experiments to do and what the results would be.

Previously, Dr. Dreyer revealed that his dyslexic imagination enabled him to visualize molecular biology and chemistry processes that led to a new and controversial theory about the human immune system. Dr. Dreyer espoused the theory for about 12 years - providing concepts based on data from instruments that he designed and built himself. However, Dr. Dreyer's data was in a form so new and unconventional that almost everyone in his field could not understand what he was talking about.

Years later, Dr. Dreyer was vindicated and proven correct. When Susumu Tonegawa was awarded a Nobel Prize (physiology or medicine, 1987) for work he had done in Switzerland, his innovative sequencing work demonstrated (through experiments that were illegal in the U.S. at the time) that Dreyer and his colleague's predictions were correct. In the words of two scientific historians of this period: 'This experiment marked the point of no return for the domination of the antibody diversity question by nucleotide studies: it was Susumu Tonegawa's final proof of the Dreyer-Bennett V-C translocation hypothesis through the use of restriction enzymes' [5].

Dr. Lindberg's views on dyslexic insight were summarized in a quotation he kindly provided for the back cover of my third book, *Seeing What Others Cannot See*.

'West argues convincingly that dyslexics . . . seem to fail in elementary school learning while excelling at the broader level of graduate school. Many whose stories he recites were smashing successes in business. West urges that this is because of extra gifts in visual learning and thinking. He goes beyond praising dyslexics' hidden strengths in visual thinking and learning, their ability to see what others cannot see - he demands that we stop hiding the imaginative strengths of all children under their weaknesses in reading.' - Donald Lindberg, M.D., Director Emeritus, National Library of Medicine [6].

5. Markle Scholars in Academic Medicine, Fifty-Year Reunion

A major conference where Dr. Lindberg and I were on program provided insights into the history of medical education. The 50th reunion of Markle Scholars in Academic Medicine occurred from September 17-19, 1998, in Phoenix, Arizona.

Other speakers included: Gerald M. Edelman, Scripps Research Institute (Nobel Prize winner), and Howard Gardner, Harvard Graduate School of Education (MacArthur Prize winner). Markle Scholars were professors identified by their medical school deans as the best teachers in the U.S. and Canada for several decades after World War II.

In my talk, I spoke primarily about visual thinking among creative scientists and some then-recent developments in computer graphic technologies. However, I also mentioned how visual thinking and associated innovation sometimes were linked to dyslexia and other related learning differences.

Remarkably, during the three-day conference, many (nearly one half of the attendees and their spouses) spoke to me about their dyslexia (two surgeons from Johns Hopkins, for example) or told stories of dyslexia among their family members or their more creative and innovative coworkers.

As I look back, I am enormously grateful for the privilege of knowing Dr. Lindberg and his wife, Mary. Rightly, it is now often said both presided over the Golden Age of the National Library of Medicine.

Dr. Lindberg's vision was broad and deep, often including early consideration of diverse topics that only later became evident within the mainstream. Don took over a massive medical library primarily designed to serve various medical specialists - and using the newest technologies, he pushed the boundaries to serve the nation and, eventually, the world.

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Working with Dr. Lindberg: A Personal Perspective

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U.S. National Library of Medicine (retired)

1. Introduction

A large organization like the U.S. National Library of Medicine (NLM) often reflects the personality or character of the person who runs it. In Donald A.B. Lindberg M.D.'s case, it was more akin to character. I rarely came across anyone who did not look forward to coming to work, myself included. My peers not only enjoyed what they did, they were also in an environment in which they received an opportunity to thrive.

I joined NLM in December 1988, a few years after Dr. Lindberg became NLM's director. I met him about six years later because of his preference for Apple products and my expertise. Dr. Lindberg eventually asked me to be his technical support assistant - and help him (and his immediate staff) with hardware and software issues. Always professional, we rarely interacted personally other than an occasional foray into current events. Then, about six years later, I was forced to involve him in my personal life when I initiated a transition from male to female.

2. Tolerance Prevailed

NLM was a socially advanced entity, in large part because of Dr. Lindberg. People were very comfortable being 'out' as gays or lesbians. It was evident that the white male hierarchy - omnipresent at the time of Dr. Lindberg's arrival - was shifting to include women and minorities among NLM's staff and management. Yet when I came out as a transgender woman, I knew there were few legal protections and institutional precedents. I was concerned about my career and very survival. During the initial months of my transition, two other institutes at the U.S. National Institutes of Health had fired two employees during their gender transition.

To back up, throughout my employment at NLM, I was an at-will contractor, which meant I could be dismissed without reason or explanation. Also, transgender was not a federally protected class at the time of my transition. Moreover, besides coming out to Dr. Lindberg and my immediate co-workers, I informed NLM's offices of personnel and employee services about my plans. To this day, I am struck by the consistent response I received from all: 'You will not be fired for this.'

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These simple words indicate NLM's senior management's character and integrity and suggest a reason why so many people admired and were loyal to Dr. Lindberg. Essentially his position was: 'there are things that you can do or not do that can and will get you fired, but who you are will never be one of them.'

My peers and I could be as quirky, different, and unique as we wanted to be, yet we were judged by the quality of our work and contributions. Indeed, Dr. Lindberg's straightforward managerial philosophy - and its tolerant underpinnings - partially explain a prevailing ethos that supported many of NLM's core achievements during his tenure. The latter include Medline, Medline Plus, Grateful Med (more on that in a moment), PubMed, Visible Human, and dozens of other projects.

3. About Dr. Lindberg

Overall, Don Lindberg may have been lauded, but he was not an egomaniac. He was HIGHLY opinionated but rarely ignored other people's ideas. His interest in seeing others succeed fostered shared responsibility, recognition, and independence. For example, after a vigorous defense of their plans and ideas, Dr. Lindberg provided significant autonomy to NLM's History of Medicine, High-Performance Computing Laboratory, and Special Information Services divisions in addition to diverse outreach and extramural programs that are discussed in this book's first three sections. The world (*yes, the world – Dr. Lindberg would have loved for it to have been called the International Library of Medicine*) is a better place for the contributions developed at NLM during his tenure.

Also, Dr. Lindberg's tolerance, openness to innovation, and interest in others generated other constructive institutional outcomes. For example, when Roy Standing (from NLM's Office of Computer and Communication Systems) developed MEDLINE's initial software, he suggested to Dr. Lindberg that it be called 'Grateful Med' both a pun and homage to the well-known band. Standing had a dry sense of humor that Dr. Lindberg appreciated. He quickly decided that a clever name should be embraced rather than quashed - even within an evidence-based federal health agency. So, the name 'Grateful Med' survived – and Standing's software (which was well-written) was both supported and sometimes celebrated by its users.

Standing was one of the many retired and active NLM staff members who attended Dr. Lindberg's retirement ceremonies in 2015. Others who attended, including Alexa McCray Ph.D. (who launched ClinicalTrials.gov) and Michael Ackerman Ph.D. (who managed the Visible Human Project), commonly appreciated the autonomy and creative space they received at NLM during Don's tenure.

Indeed, NLM's success derived from Dr. Lindberg's eagerness to see others succeed, his tolerance and support of diversity, and his interest in employee creativity and innovation. I was one of many beneficiaries - and I salute Don's character, contributions, legacy, and memory.

Dr. Lindberg: An Enduring Source of Inspiration

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1. Introduction

The most vivid impression I retain about Donald A.B. Lindberg M.D. is the sheer breadth of his vision for the National Library of Medicine (NLM) and indeed for the medical community. Dr. Lindberg's insights and contributions to medical informatics and related fields are well established, but equally remarkable was his philosophy of 'Let a hundred flowers bloom, let a hundred schools of thought contend' (credited initially to Mao Zedong) when it came to NLM.

Dr. Lindberg envisioned opportunities far beyond the confines of a traditional medical library and of medicine itself. He perceived NLM and its many and diverse arms as vehicles to ultimately enrich people's lives in America and around the world.

Much of Dr. Lindberg's vision translated to projects across NLM, including several in the Communications Engineering Branch, part of the Lister Hill National Center for Biomedical Communications' Engineering Branch, an NLM research division. I began as an engineer in the branch in 1974 and had the privilege to lead it from 1984-2018. I outline some of these initiatives in this article, emphasizing Dr. Lindberg's critical role.

2. Curiosity Befitting a Renaissance Man

To come to my memories of Dr. Lindberg, one of his most enduring (and endearing) characteristics was his curiosity. He was interested, without a doubt, in everything!

For example, when Dr. Lindberg discovered I wrote a couple of papers on image compression, he wanted to know more. Compression became necessary as my team scanned documents and x-rays for several ongoing projects. This resulted in very large files that seriously challenged both networks (for transmission) and storage devices (for archiving). Dr. Lindberg expressed interest in the design of our compression algorithms, which I tried to explain through diagrams and equations. Years later, when speaking at my retirement in 2018, to my surprise, he recalled this work – though honestly, I had forgotten most of the details.

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Dr. Lindberg's insatiable curiosity led him to topics far afield. For instance, he learned a colleague, George Fonger, was a fossil hunter with a background in paleontology. While Fonger's job at NLM's Specialized Information Systems division had little to do with the latter discipline, Dr. Lindberg enjoyed studying the marine fossils dug up from the banks of the lower Potomac River. The fossils included shark teeth and oyster shells from the Paleocene era. Fonger affectionately recounted their conversations as I joined him in collecting these artifacts on summer trips at a site near the Chesapeake Bay.

I suggest curiosity also led Dr. Lindberg to explore the Internet and to understand how important the network would turn out to be, far earlier than other physicians and scientists - including the leadership of the National Institutes of Health (NIH) and its institutes and centers. Regarding Internet assistance, Dr. Lindberg sought the best and the brightest in this area as in many others, but also invited innovative pioneers to share their knowledge with the staff. I remember talks in NLM's auditorium by Bob Kahn and Vincent Cerf - both widely credited for the origins of the Internet. From these luminaries and others, Dr. Lindberg foresaw the potential of the Internet as a game-changer in the search for and delivery of medical information. In a relatively short time he introduced Medline, NLM's flagship database, as a free service available on the Internet, a boon for clinicians and researchers worldwide.

3. Pushing the Envelope - Early Recognition of the Power of Artificial Intelligence

In the winter of 1995-96, Dr. Lindberg paid me an unexpected visit that had a far-reaching effect on my career as well my colleagues who worked in Lister Hill's engineering branch. Specifically, the meeting encouraged us to enter the new, burgeoning field of machine learning, a subfield of the discipline referred to as Artificial Intelligence.

Dr. Lindberg explained NLM was experiencing a crisis. Politicians in downtown Washington DC were unable to stave off a U.S. government shutdown, which adversely interrupted one of NLM's primary health informational/educational services and required an innovative intervention. Specifically, NLM's contract for data entry was suspended by the shutdown, which meant staff was not entering bibliographic data into Medline. The latter resulted in a hiatus updating and maintaining the database of citations to the medical journal literature. Hence, Medline, the world's most critical and possibly life-saving medical information resource, was neither up-to-date nor optimally serving the world's medical and research communities.

Something needed to be done.

Dr. Lindberg immediately asked if our ongoing document imaging and optical character recognition (OCR) work could be refocused to extract bibliographic data from scanned articles automatically. I explained OCR would be a first step to convert pixels to text. Still, algorithms would be necessary to identify and extract author names, article titles, abstracts, author affiliations, and the like – all vital elements of Medline citation records previously manually entered.

Not only did Dr. Lindberg give me an immediate go-ahead, he directed the Library's indexing section to cooperate in this effort. Thus, the MARS project – a hastily contrived acronym standing for Medical Article Records System – was born with urgency as well as a compelling professional purpose.

Dr. Lindberg was well aware of the pioneering nature of our efforts to develop machine-learning algorithms. Understanding the difficulties ahead, he said, "You folks do great engineering, but I hope you can do good computer science." I knew Dr. Lindberg meant that developing innovative algorithms and software was different from building systems based mainly on hardware, which was the branch's focus at the time.

Yet, we persevered and developed the first machine-learning algorithms that successfully automated the extraction of bibliographic data from journal articles for the next 20 years. Moreover, this early work set the stage for 25 years of contributions to machine learning (and later, deep learning) that was applied to other areas, such as the automatic identification of diseases (TB, malaria, cervical cancer) in medical images. In a very real sense, Dr. Lindberg's set priorities helped shape our own. He created the conditions that enabled Sameer Antani, Rodney Long, Stefan Jaeger, and many others in my branch to build advanced diagnostic systems and to publish hundreds of peer-reviewed publications over the years – an effort that endures.

Although Dr. Lindberg supported the MARS project, he was prudent, which was another of his managerial attributes. To discover alternative automation approaches, Dr. Lindberg reached out to his friend Raj Reddy, the director of the Robotics Institute at Carnegie Mellon University. In 1996, Reddy identified a colleague, Robert Thibadeau, to whom we sent a few thousand images of the articles we used in our research. It turned out Dr. Thibadeau's proposed strategies were not materially different from our approach, and NLM abandoned work with his group. Yet, the incident struck me as emblematic of Dr. Lindberg's leadership. Although Dr. Lindberg was loyal to NLM, he was never parochial. He always prepared to look outside NLM for expertise and advice that would advance the Library.

4. A Respect for NLM's Historic Treasures

Dr. Lindberg's deep understanding of NLM's unique strengths included an appreciation of its historical collections, specifically the 'treasures' kept within our History of Medicine Division (HMD). Dr. Lindberg mused about the possibility of revealing these treasures to the public without letting people handle centuries-old medical books - for the obvious reasons that each is fragile and unique.

In the early 2000s, Mike Chung and Glenn Pearson, my branch colleagues, tackled image animation as a way to bring these treasures to life. Chung was a world-class computer graphics expert, and Dr. Pearson, a talented software developer. They formed a symbiotic relationship crucial to develop *Turning The Pages* (TTP). TTP is a computer program that facilitates the 'touching and turning' of a book's (scanned) pages, which gives a reader an almost realistic look and feel of the original.

To initiate TTP's development, we talked to HMD's Michael North, who selected some rare 16th-century books from the Library's historical collection. These included Vesalius's anatomy masterpiece, Gesner's studies on animals, Paré's book on surgery, and many others. North proposed he serve as a curator and provide notes as well as explanatory material to improve a reader's understanding of the accompanying text.

It should be noted that although the software for NLM's TTP was our own, the inspiration for it was a system with the same name created by the British Library. Dr. Lindberg and Kent Smith, NLM's then-deputy director, had encouraged me and Joe Fitzgerald (a talented graphic artist at the Lister Hill Center) to visit the British Library to see their system and perhaps use their software. Although the British Library staff

were unfailingly congenial and wonderful hosts, I formed the impression that we would need to develop TTP on our own, which we did.

To reach a broad audience, NLM's TTP was created in different forms: software for a touch-sensitive monitor, a Web program, and software for iPads and iPhones. The monitor went into an elaborate hardwood cabinet in the Visitors Center on the Lister Hill building's first floor and proved to be popular with school children and adults visiting NLM. The Web program was readily accessible by patrons anywhere on the Internet, and hundreds downloaded our software to view the books on their iPads and iPhones.

5. Ever the Francophile

In about 2010, TTP underwent an exciting transformation that we anticipated would delight Dr. Lindberg. Guy Cobolet, the director of an important medical library in Paris (BIUM), was spending a sabbatical at NLM hosted by Michael North. Intrigued by North's description of TTP, Guy paid me a visit during which I suggested a French version of TTP.

I knew Dr. Lindberg as a Francophile would be interested, if not thrilled. Cobolet agreed to translate North's curatorial notes as well as the names of the controls on the displayed images. In turn, we created *Tournez Les Pages*, which was invoked by a click on a French tricolor on the TTP Web page (a click on an American flag brought the reader back to the English version.) With a slight dramatic flair, I showed the system to Dr. Lindberg on Bastille Day, the 14th of July, and as expected, he was more than pleased. Thanks to Cobolet, we converted several books into the French version of TTP. However, we did not complete the entire collection since he returned to Paris for his day job. As Cobolet would have said: "C'est la vie!"

I knew, as others did that Dr. Lindberg had a love for French culture and language. Indeed, once at a meeting in his office, I mistakenly used Marseille (the city) for La Marseillaise, the French national anthem. Ever the teacher, he quickly corrected me, as my dad would have done - had my dad known French (which he did not). I felt that in educating me, Dr. Lindberg was acting instinctively in a parental role, an attitude that forever endeared me to him.

6. NLM's Role in Global Disasters

Always taking a macroscopic view of NLM's role in the world, Dr. Lindberg established disaster information and mitigation as new activities, primarily centered at NLM's Specialized Information Systems division. While large-scale disasters may not seem a natural fit for a library, Dr. Lindberg recognized that health information and tools were necessary to overcome the devastation that resulted from earthquakes, tsunamis, floods, and similar events. And health information and tools were indeed the province of NLM and its many and varied talented personnel.

In January of 2010, Haiti suffered a significant earthquake with hundreds of thousands of casualties. Pondering what my branch could do, I talked to Mike Gill and other colleagues. Although I did not know anything about disasters, I was confident parents would be looking for missing kids, friends for each other, and wives for their husbands for the immediate aftermath of a disaster.

Consequently, we developed People Locator, a Web site that served as an electronic bulletin board where photos of missing people (and their names and ages) could be posted by friends and family, so others could report whether they were safe or not. Tens of thousands of photos of missing Haitians were posted and confirmed whether or not they were alive and well. The system was subsequently deployed in about 50 disasters worldwide until 2018, when we decided that social media could assume this role. However, the development of People Locator was a direct consequence of Dr. Lindberg's concern for people's lives and wellbeing and the atmosphere that he fostered to provide innovative solutions to health information barriers.

7. NLM as Family

From the moment he arrived at NLM, Dr. Lindberg took ownership of the institution in a deeply personal way. He treated staff as family. Every December, everyone was invited to the Christmas party hosted by Dr. and Mrs. Lindberg with handshakes and hugs all around (though hugs were received only from Mary!) This welcome year-end celebration often was graced by music. We had a troupe of gospel singers one year and staff member Earl Simmons singing solo in his deep baritone at other times. I also remember an accordion player and bell ringers from a nearby Kensington church. All were wonderful entertainments marking the holiday season and the end of another year in what has been called the 'Golden Age' of the National Library of Medicine.

Dr. Lindberg's vision of NLM as a family also is evidenced by two panoramic group photos of the entire staff - on both occasions in front of the main library building. The first picture was taken a year or two after his arrival. The second photo captured the staff gathered to form the number 175 in commemoration of the 175th anniversary of the Army Surgeon General's Library - NLM's direct ancestor. Everyone on the staff, perhaps with a few exceptions, was included in both photos. In retirement, I cherish these photographs with the familiar faces I knew for so long.

8. Last Thoughts

It is hard to precisely gauge the impact of what parents or mentors do for us at the moment of their influence. But in retrospect, looking back on the years of support, guidance, advice, and even criticism, their contributions to one's growth and success seem more evident. So it has been with my remembrances of Dr. Lindberg. In filial affection, I write this memoir.

My Journey with Donald A.B Lindberg M.D.

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1. Introduction

Donald A. B. Lindberg M.D. was my friend, my colleague, someone I looked up to, but most importantly, a man with whom I could comfortably share confidences.

We spent quality time together at the National Library of Medicine (NLM), at meetings, dinners, at the Woods Hole Conference, and during national and international travels. We enjoyed many evenings, relaxing in a restaurant, and especially at Don and Mary Lindberg's home.

We relived memories of growing up in Brooklyn. We chuckled over the fierce competition between "D'EM BUMS" fans (the Brooklyn Dodgers), and the pin-striped, pompous, New York Yankees. The N.Y. Giants? They were simply the 'other team.' We reminisced about Coney Island, the wonderful museums, parks, riding the subway, and biking to ride the Staten Island Ferry. We remained awed by the Empire State Building, Central and Prospect Parks with their zoos, Broadway shows, Radio City Music Hall, and on and on and on.

We rarely repeated ourselves as the experiences were nearly unlimited. I admit these memories became more vivid, expansive, and colorful when our discussions were augmented by a few of Don's bourbons with branch water.

Although we never solved the world's problems, we were not shy to address them. Thankfully, Mary Lindberg monitored my evening sessions with Don. She fed us delicious dinners, and on occasion, guided Don to bed and me to a spare bedroom.

The memoir's next sections address a few topics that touch on our friendship. The topics include: how and when I met Don; how his work impacted my career as a cardiovascular surgeon two decades before we met; impromptu days off with Don on a boat in the Potomac river; his ongoing professional support; and a closing tribute.

2. How We *Really* Met and Quick Responses

In 1993, I was practicing cardiac surgery in Des Moines, Iowa, geographically located in the north central U.S. My office messaged me that: 'Dr. Donald Lindberg, the Director of the National Library of Medicine' was trying to reach me. The name 'Don Lindberg'

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rang a bell, but I could not recall why. The long hiatus between our first meeting and my initial exposure to Don is discussed in the next section.

Intrigued, I returned Don's call. To my surprise and delight, he invited me to serve on NLM's Board of Regents (BOR). The BOR met three times a year at NLM in what is now called the Lindberg Board Room.

Each meeting was, in my mind, at the level of a postdoctoral seminar in biomedical informatics. A BOR membership lasts four years, and I was the chair when I rotated off in 1998. To my delight, Don asked me to continue as a 'Consultant to the Board.' I was captivated with NLM's innovative projects and programs and its world-class staff, and I felt honored to remain connected.

A year later, when Harold L. Schoolman M.D. (NLM's Deputy Director for Research and Education) retired, Don invited me to fill the position. Don's invitation was on a Wednesday afternoon – just after a BOR meeting adjourned. I accepted on the spot.

Don asked when I could start and was startled when I replied: 'probably Monday.' At the time, Don was unaware my daughter just completed a master's program at American University and was flying off to begin a doctorate program at the University of Washington-Seattle. She left an empty, unsold, move-in immediately apartment, about a mile from the NIH campus.

So, I started on Monday.

3. How We *Almost* met - or Like Two Ships Passing in the Night

Don's innovative thinking and achievements impacted me about two decades before my invitation to join NLM's Board of Regents. Yet, my initial exposure to Don's work was linked to a career job change.

In 1974, I was recruited from the University of Oregon by the staff and administration of Mercy Hospital in Des Moines to establish a cardiac surgery program. At the time, the Mercy Hospital and Clinics serviced a population of approximately 700,000 people. The nearest heart surgery program was about 100 miles away. Des Moines patients and their families were forced to travel regionally (south to the University of Iowa or north to the Minnesota-based Mayo Clinic) for cardiac surgery.

In short, my new job was a response to a need for better, local access to cardiac care coupled with Iowa's harsh winters, which often jeopardized regional travel for patients and families.

To prepare for my arrival, the hospital flew my future Des Moines clinical team to train with me in Oregon. The goal was to teach my Des Moines team to collaborate similar to the heart surgery group I was leaving at the University of Oregon. The remote training activity was designed to enable us 'to hit the ground running,' which was critical. Before I arrived at Mercy, I had a waiting list of 84 patients.

Yet in team building, I did not set up a modern pathology laboratory to support our new surgical group. As busy as I was on day one, it was apparent that Mercy Hospital's cardiac team would not thrive if we failed to prepare the hospital's pathology laboratory optimally to assist a suddenly very active surgical unit.

I quickly learned that the University of Missouri had a world-class laboratory and pathology program that supported the university's clinical center. I cannot describe our Des Moines laboratories deficiencies better than to suggest our technology was

equivalent to a vacuum tube TV with rabbit ears, while Missouri's pathology technology was 5K.

In turn, arrangements were made for our in-house pathologists and technicians to visit the University of Missouri's Hospital and Clinics (in Columbia, Missouri) to learn how to upgrade Mercy's laboratory practices. What I did not know then (and discovered later) was Mizzou's lab was under the direction of Donald A. B. Lindberg M.D., a Professor of Pathology and Director of the Information Science Group - University of Missouri-Columbia.

While we did not meet until almost two decades later, I became aware of Don's work and skill because he provided a template and the training to modernize Mercy Hospital's pathology laboratory, which boosted my cardiac surgery program.

4. Adventure on the Potomac

Despite years of clinical influence and institutional collaboration, it was not always work with Don.

For example, we took an impromptu trip once during a typical, sweltering, middle August in Washington D.C. when I was director of NLM's Special Information Services Division (SIS) division - my second administrative position at NLM.

The voyage began on a Tuesday morning, when I routinely met with Don in his office on the NIH campus. Since it was a short drive from my Democracy Blvd. office to Don's office in building 38, there was insufficient time for the car's air conditioning to kick in. In addition, just the walk from the parking garage to the mezzanine area (where his office was located) left me in a pool of sweat. As I slumped into Don's office, he took one look at me and said, 'boy, it's hot and humid.'

At the start of the meeting, Don mentioned Mary was out of town for the week. I said so was my wife, Susan. Grinning mischievously at each other, we instantly came up with the idea of playing hooky. After a brief pause, Don said 'BOAT.'

I responded: 'Don… you bring the food and libations, and I will be responsible for the gasoline.'

In moments, a plan was hatched! We informed our respective staff that we were unavailable for the next few days (Wednesday through Friday). We designated our responsibilities to our deputies and disappeared.

We met at a Marina at about 10:00 am the following morning. We gassed-up stored our provisions and set sail. The temperature was already inching toward the mid-90s, with no breeze with the humidity at least 300%.

I started to organize the galley but found the cabin stifling hot. To avoid heatstroke, I asked Don to turn on the air conditioning. Don unsuccessfully fooled with some switches and knobs, then informed me he was unsure how to turn it on: 'that Mary usually did it.' After 30 minutes of flipping switches, Don gave up, so I began looking for the rescue markers and flare gun. It was evident that we were going to rough it for a while.

Did I mention the boat's engine would not start? It finally fired up when we discovered that we had to prime the gas feed.

Off we went, cruising down the Potomac, toasting our escape with a cocktail. We were relaxed with not a care in the world until a couple hundred thousand hungry mosquitoes attacked us. Don, an experienced and seasoned sailor, responded immediately. He hit the gas and left the swarm behind us.

We both agreed that the best response to the attack was another bourbon.

The afternoon passed, the breeze picked up, and some ominous rain clouds appeared. When we reached an area opposite the Quantico Marine base, we were greeted by a welcome cool drizzle. I took a quick refreshing dip into the Potomac then dutifully rejoined Don to help finish the first bottle of bourbon. When the rain began to squall, we ducked into the cabin and closed the door and hatches to prevent the many gallons of rainwater from flooding the cabin.

Again, without success, we tried to turn on the air conditioning. In turn, the only answer to the latter predicament was to mix martinis.

The rain stopped, so we opened the cabin to the outside. Cool air flooded in comfortably around us.

We chatted, enjoyed a cold supper, and yawned. Don mumbled something about getting into bed, and I chose to sleep on deck. We awoke just after sun rise. I gathered up some breakfast while Don busied himself with coffee.

We spent a good part of the day fishing, but the fish were luckier and smarter. We discussed everything from Kipling to politics and the opera. We again reminisced about growing up in New York City, the Statue of Liberty, ethnic restaurants, and other common experiences. After much discussion, we agreed that the N.Y. Museum of Natural History was one of our favorites.

Throughout the day, we shared stories about our adventures in life, college, medical school, and how much we missed the multicultural and multiethnic environment of New York. We agreed that living in Missouri and Iowa also was amazing and how neither of us regretted the range of our experiences. I described to Don the beginnings of my cardiac program and the contributions of his pathology lab.

He smiled.

By Friday afternoon, we ran out of food and drinks. We looked at each other and agreed this great adventure was over, and it was time to go home. We honestly had fun, although we both required a weekend of rest to recover.

5. Don Had My Back

Don's enduring support is illustrated by explaining when he substituted for me and requested that I return to NLM following a prior exodus.

To backup, NLM initiated a program to educate high school students on careers in the medical sciences during my term as NLM's Deputy Director for Research and Education. The conference was named after Michael DeBakey M.D., the distinguished heart surgeon and medical educator and a long-time member of NLM's Board of Regents.

Indeed, the first students in the program were from the Michael E. DeBakey High School for Health Professions in Houston, TX., where Dr. DeBakey then lived.

Subsequently, NLM sponsored DeBakey conferences in other cities that were piggybacked onto a scheduled conference of medical professionals. The simultaneous scheduling was so we could ask prominent scientists attending the conference to meet with students. No requested speaker ever refused.

One of the venues selected for the DeBakey conference was in Chicago during the 2004 annual meeting of American Society for Artificial Internal Organs (ASAIO), an organization I was professionally affiliated with. After I left NLM and the Deputy

Director for Research and Education position in 2002, I continued to manage the DeBakey conferences (with NLM's support).

All the arrangements for the DeBakey conference were in place. The students were selected, parental permission slips signed, transport to the conference arranged, and the speakers primed and ready. As usual, I was both a facilitator and moderator.

However, I had a medical emergency the day before my Chicago departure, which required immediate surgery. Since I was in Iowa instead of Bethesda, no one at NLM was aware of my unexpected incapacitation. My wife Susan called Don and explained my impending absence.

Don immediately came to the rescue. He dropped everything, canceled all plans, and flew to Chicago to host the DeBakey conference, AND he called Susan daily to check on my progress.

The second example of Don's support was his invitation to me to return to NLM in 2006. The offer was significant because I left NLM in 2002 in a departure that I soon determined a mistake. Don was not happy with my 2002 exit, and we rarely communicated for a short period.

Nevertheless, in 2006 I was asked by the National Heart Lung and Blood Institute within the National Institutes of Health to consider leading a new Division. I called Don for advice, and he said something to the effect of: 'to hell with that… come back to NLM.' I was delighted, and I returned as the director of NLM's Specialized Information Services division.

From my perspective, Don's actions in both circumstances say everything about him.

6. Epilogue, My Two Cents

Broadly speaking, if I had to describe Don with one word - it would be ARTIST. Don expressed his artistic bent through many creations and accomplishments, and often beautifully with a camera.

Artistry enables a person to see the beauty, the good, the potential, and the benefit in people, things, and processes. Some examples include Don's ongoing support for students, minorities, and individuals trying to better themselves. Don promoted, enhanced, and actively supported a diverse and abundant array of imaginative programs and projects at NLM.

However, an artist also perceives the 'ugly.' Don spent his career addressing 'ugly' examples that adversely impacted medical practice and the public. These included: dysfunctional health information technologies; occasionally parochial actions by medical stakeholders; unstructured clinical data; the enduring challenges that limited user access to printed medical journals and books; the monetization of the Internet; and disconnected medical libraries, among others.

With a multidimensional perspective, Don succeeded and improved access to health information at every level.

Beyond NLM, Don contributed intellectually to many organizations, including his favorite, the Cosmos Club in Washington, D.C. He encouraged others to do so.

Don's achievements were visionary, engendered by a caring intelligence, to promote public education and support physicians, nurses, pharmacists, and other healthcare workers. He wanted NLM's resources to enable provider self-improvement and enhance

patient care. He also envisioned NLM's resources as helping patients and their families understand medical information and the health care delivery system.

THANK YOU, DON!

Dr. Lindberg's Talented Assistant – An Interview with Pat Carson

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Keywords: Donald A.B. Lindberg M.D., U.S. National Library of Medicine

Patricia (Pat) Carson was Donald A. B. Lindberg M.D.'s Senior Executive Assistant for more than three highly productive decades.

'I loved working for him,' Pat said in a May 2021 interview.

Among other efforts, Pat helped organize the NLM Board of Regents meetings, the NLM Holiday party, some of the Friends of the National Library of Medicine activities, many of the Library's visitors/speakers and Dr. Lindberg's travel and schedule. Other memoirs explain the array of speakers, social, and other events that Pat coordinated provided part of the stimulating, family atmosphere which NLM employees enjoyed for more than a generation [1-2].

Looking back, Pat highlighted the behind-the-scenes preparation for the opening of NLM's Frankenstein: Penetrating the Secrets of Nature exhibition, which Dr. Lindberg described as one of his most memorable evenings at NLM.

Pat explained organizing the Frankenstein exhibit opening was special because it allowed her to display her expertise in historical costumes. The Frankenstein exhibit's opening featured a costume gathering. Pat owned a costume store in Maryland, which especially flourished during Halloween and holiday seasons.

NLM's Frankenstein exhibition was partially inspired by Mary Shelley's story (in 1816), which introduced some of the scientific advances of her era and raised issues about the socio-cultural impact of unchecked power and self-serving ambition [3]. The exhibition provided an evidence-based platform to update and appreciate some of the aforementioned issues.

For the Frankenstein opening, Pat furnished a Louis XIV 'sun king' costume for Dr. Lindberg and helped dress Mary Lindberg as 'Marie Antoinette.' Pat said it was a challenge to find a faux sword to accompany Dr. Lindberg's costume and a wig to complete Marie Antoinette's look.

Mary Lindberg, who participated in the Carson interview, explained she returned with Dr. Lindberg from a trip to Charleston, SC, on the afternoon of the Frankenstein exhibit's opening. Mary recalled she proceeded directly from the airport to the event where Pat readied their costumes.

Before the trip, Mary decided it would be fun (and appropriate) to adorn her Marie Antoinette costume with an in-character cake. Mary explained she placed a Limoge cake plate in her luggage and planned to buy a cake in the afternoon before the event.

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However, Mary's plans almost backfired when she could not find a cake to buy in the airport during her return trip to Washington. Eventually, a Starbucks employee reluctantly agreed to sell the coffee store's supply of cake slices.

When the Starbucks employee asked Mary why she insisted on buying *all* the remaining slices, she responded: 'I'm attending a costume party as Marie Antoinette tonight in Washington.' While the employee remained semi-incredulous, Pat noted the pastries indeed complimented Mary's costumed character.

Incidentally, Mary presented the plate to Pat on her retirement from NLM.

Overall, 'Dr. Lindberg looked stately, and Mary looked gorgeous!' Pat said.

Pat also reminisced about two occasions where her improvisation enabled NLM meetings to proceed smoothly. In the 1980s, after extensive planning for an NLM-sponsored international biomedical informatics conference, the catering staff failed to show up for an attendee dinner. Pat explained she was forced to organize volunteers on the spot to cook and serve a meal for more than a thousand people, many of whom never knew about the evening's potential culinary catastrophe.

On the mid-morning of September 11, 2001, a planned, catered luncheon for the NLM Board of Regents was canceled because NLM (and NIH) were forced to close mid-morning. (More about the events on the morning of September 11th are described in two of the book's memoirs) [4-5].

As the day's dreadful news accumulated, Pat realized the Board members who lived outside of Washington would be trapped without a way to travel home - and Washington area restaurants would be closed. She and Mary responded by inviting the stranded Board members and meeting participants to the Lindberg's residence that evening. However, Pat realized a dinner for the invitees necessitated serving the food initially planned for lunch.

Pat packed all the food and moved it to Dr. Lindberg's convertible – and somehow averted spoilage. Fittingly, some of the guests at the impromptu dinner never knew their evening meal was transported and repurposed.

Pat's ability to organize activities and work with others remains so respected that people who assisted with NLM events frequently inquire about her welfare - years after retirement. During a recent visit to a local French restaurant (where many NLM occasions were held), its veteran maître d' asked Mary: 'how is Pat Carson?' 'This happens all the time,' Mary exclaimed. 'Those who worked with Pat remember her so fondly'

Mary added Pat's admirers include the members of the Lindberg family, many of whom know Pat well.

Otherwise, during the era they worked together, Pat often described Dr. Lindberg as demanding but fair, dedicated but understanding, and highly focused but tolerant.

Besides Dr. Lindberg, Mary, and Donald West King M.D. (NLM's long-time Deputy Director), Pat lauded working with NLM staff members Kathy Cravedi, Janet Laylor, and David Nash. Pat quickly smiled and applauded when she mentioned each of their names. Pat added she keeps in touch with all three.

'Yes, NLM was a busy place, but it often was fun,' Pat said.

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Don Lindberg's Home Library and Leadership Traits

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Abstract: This chapter introduces the importance and some of the multidisciplinary diversity in Donald A.B. Lindberg M.D.'s home library. The latter collection minimally suggests his varied interests, which often inspired a multidisciplinary approach to tackling problems and managing the U.S. National Library of Medicine (NLM). Dr. Lindberg converted the ideas he picked up from reading into administering projects as well as to set aspirational goals for NLM and for himself. The chapter suggests Dr. Lindberg's home library was an enduring reservoir of knowledge, judgment, planning, and creativity. The chapter also discusses two of Dr. Lindberg's leadership traits: the cultivation of discovery and project development in educational administration and the need for leaders to determine and act in the greater public interest. The chapter suggests the latter two traits defined Dr. Lindberg's NLM leadership.

Keywords. Donald A.B. Lindberg M.D., leadership, vision, administration, public interest, U.S. National Library of Medicine

1. Introduction

Honolulu's humidity was nearly incapacitating as Donald A.B. Lindberg M.D. and I waited in the cheerful home library of a Native Hawaiian physician. We were there to interview him for the National Library of Medicine's *Native Voices* exhibition in spring 2011 [1]. While our host was busy with a patient, Dr. Lindberg and I were grateful for a quiet moment in a pleasant setting with air conditioning. With a burst of enthusiasm and a bit of mischief, Dr. Lindberg said: 'let's peek at the bookshelves.'

As we perused, Dr. Lindberg kept calling me over to look at a volume of Hawaiian or Polynesian history. 'I've heard of this book, he exclaimed, *never* seen it.' Each new discovery provided an opportunity to be relished. After a few minutes, Dr. Lindberg said, 'This is as much fun as the Bishop museum.' He later told me his enthusiasm for the Native Voices project was so renewed by the experience (and a chance to cool off) that the subsequent interview became secondary.

Fittingly, a chapter of personal reflections about Dr. Lindberg's leadership and character should begin where his inspiration flourished - in *his* home library.

This chapter briefly introduces the importance of - and some of the multidisciplinary domains - in Dr. Lindberg's library. Building on its diversity as a managerial reservoir, the chapter discusses two of Dr. Lindberg's leadership traits: the cultivation of discovery

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and project development in educational administration and the need for leaders to determine and act in the greater public interest.

2. The Importance of a Home Library

Turning first to Dr. Lindberg's home library, the collection minimally suggests his varied interests, which often inspired a multidisciplinary approach to tackling problems and managing the U.S. National Library of Medicine (NLM).

Don often told me the enduring impact of a well-chosen library was significantly greater than the sum of its parts. The process of reading triggered his thinking about how to address current challenges and often yielded imaginative ideas and approaches. He left notes to himself in some books that are windows into his thoughts at the time, which are noted in some cases below. To wit, Don's favorite bookmark translated the word 'think' into 22 languages including Chinese, Japanese, Hebrew, Greek, Arabic, and Hindi.

When appropriate, Don converted the ideas he picked up from reading widely into administering projects and often to set aspirational goals for NLM and for himself.

For example, Don began reading about the hokule'a (the Hawaiian language name for an indigenous ocean-capable catamaran) long before he launched the Native Voices project at NLM. The books he read suggested the hokule'a was an enduring socio-cultural symbol of courage, applied intelligence, curiosity, progress, creativity, and well-being among Native Hawaiians [2]. His reading also suggested few persons outside of Polynesian and Native Hawaiian communities appreciated the hokulea's historical and contemporary socio-cultural significance.

With the latter understanding, Don insisted on meeting with some of the navigators (who reintroduced the hokule'a to contemporary Hawaii) during an initial 'Listening Circles' trip years before the Native Voices exhibition opened. (FYI: The navigators were the first 20th century Native Hawaiians to build a hokule'a using indigenous materials. At first, the navigators successfully sailed to Polynesian destinations and eventually they crossed some of the world's other oceans).

From his reading and preparation, Don gleaned that getting to know some navigators was as or more important than visiting with Native Hawaiian physicians, public health officials, healers, political leaders, and dignitaries. Don understood if Native Voices was going to be perceived as a constructive initiative by Native Hawaiians, a strong relationship needed to be established between NLM and Hawaii's hokule'a navigators (who included some dauntless physicians).

Eventually, Don arranged for a replica of a hokule'a to be built by Native Hawaiian crafts-persons. It was displayed for several years in the exhibit hall of NLM and eventually returned to Hawaii (in conjunction with the lifespan of the Native Voices exhibition). The exhibition also included paintings of historic and contemporary voyagers by the late Native Hawaiian artist Herb Kane. Parallel efforts occurred with Alaska Natives and some American Indian tribes to establish trust and enhance engagement. Some of the latter initiatives are detailed in other chapters in this book [3].

Yet, it was Don's extensive reading that helped him plan some of the elements within the Native Voices project. His preparation also provided a foundation to assess the advice he received from Native Hawaiian consultants. In Hawaii and elsewhere, Dr. Lindberg's home library was an enduring reservoir of knowledge, judgment, planning, and creativity.

3. The Topics in His Home Library

Three of the most striking things about Dr. Lindberg's home library are: a) the volumes devoted to biomedical informatics and pathology (his clinical specialties) are significantly outnumbered by books about other sciences and the humanities; b) the collection's multidisciplinary range; and c) the books he authored/co-authored are hard to find.

Besides bioinformatics and pathology, the Lindberg library consists of topics that include: medical practice; history of medicine; history of science; science's social impact; higher education; the social impact of information technology; World War II; the U.S. Civil War; U.S. presidents; indigenous Americans; mass media; literature; opera; classical music; art; photography; children's stories; and travel and culture. Incidentally, the criteria to pick the latter topics was 10 or more books on the subject. Often, there were many more…

Briefly, in medical practice, the Lindberg library consists of often-consulted books about pathology, including Florey, *General Pathology* 4th and 5th edition and Anderson, *Pathology*, Volumes One and Two [4]. In biomedical informatics, the collection varies from books with a narrower focus, such as on nursing informatics, to broader research overviews. A 2006 biomedical informatics research roundup textbook begins: 'Dedicated to Donald A.B. Lindberg, whose innovative research and vision leadership of the National Library of Medicine have transformed both the field of biomedical informatics and the institution to which he has dedicated much of his professional life' [5]. The dedication is autographed by its co-authors, Ted Shortliffe M.D. and Jim Cimino M.D., who also provide significant contributions to the current book [6].

There is an extensive collection about the history of medicine. It includes a 20th century book of Leonardo da Vinci's drawings of the human body - and da Vinci's signature is reproduced on the upper right corner of the second page [7]. The history of medicine collection includes a reprint by the New York Academy of Medicine of *Morgagni's Seats and Causes of Disease* (three volumes) that originally was published in 1769 [8]. There are several books about William Osler including both volumes of Cushing's biography [9]. Other histories about the life and contributions of leading physicians include books about John McGovern and by Bernadine Healy as well as books co-authored by Louis Sullivan M.D., who contributes the current book's foreword [10-13]. The history of medicine collection is supplemented by books about medical care during the U.S. Civil War and wilderness medicine. A book that Don kept close to his desk features French artist Honore Daumier's 19th century drawings about medical care, treatment, and physicians [14].

The Lindberg library's history of science collection includes several books about Charles Darwin as well as the books Darwin authored [15]. There is a half century old copy of *The Double Helix* and an original (and often-consulted) copy of Darcy Thompson's *Growth and Form* [16-17]. A coffee table book about landmarks of western science, published by the Library of Congress in 1987, features this inscription from its author Leonard Bruno: 'To Don with admiration for what he has done to perpetuate and enrich the traditions of science' [18].

The Lindberg library contains a spectrum of perspectives about science's social impact and includes books which represent diverse sides of 20th century debates about science and social progress. Some authors on the critical side, include C Wright Mills, Peter Berger, and Jacques Barzan. Writing in the mid-20th century, Barzan found science imposes itself as a single, deterministic mode of thought upon all experience - partially

because of social inertia to counter its impact. Barzan was similarly critical of the arts [19].

Don writes at the end of a chapter where Barzan critiques modern art: 'art has stressed the bizarre to shock us … this is ok - but modern art is bizarre in ways which mimic the sciences in point of view'... [19].

The Lindberg collection also contains C.P. Snow's book about the two cultures in higher education, which sparked a 20th century debate if the education of college students in the sciences or the humanities was so one-dimensional that it furnished a tacit risk to socio-cultural progress [20].

In contrast, some books in the Lindberg library (especially by Rene Dubos and Jacob Bronowski) note the constructive role of science in the creation of knowledge, the role of scientists in fostering a better quality of life, and furthering innovations and creativity in society and culture [21-22]. In Bronowski's book, *The Origins of Knowledge and Imagination,* Don underlines this passage: ' the most interesting thing about man is that he is an animal, who practices art and science and in every known society, practices both together [21].' Incidentally in this and other books, Bronowski criticizes some scientists Don respected including paleoanthropologists Konrad Lorenz and Robert Ardrey.

Environmental quality is the only scientific topic where a balance of perspectives is missing. The Lindberg library includes an earmarked copy of *The Silent Spring* and similar books about ecological decline [23]. In the *Silent Spring's* acknowledgements, Dr. Lindberg underlines: 'every writer of a book based on many diverse facts owes much to the skill and helpfulness of librarians' [23]. The acknowledgements go on to thank a librarian at the National Institutes of Health, which Don also underlines. Inside the book, Don inserted some clippings from the *Wall Street Journal* about the environmental harms of pesticide use.

Similar to most other areas, the Lindberg library features an admixture of critical and more favorable books about the goals of higher education and the impact of information technology on society. Some books, such as a late 20th century update to John Henry Newman's *The Idea of a University*, present a more favorable view than Snow regarding the socio-cultural impact of emphasizing degrees in professional and scientific training juxtaposed with liberal arts and general education [24]. Don left a bookmark and underlined parts of Newman's original preface where he notes the diffusion and extension of knowledge are as important as its advancement. The latter yields insights into Don's managerial vision to produce, diffuse, and extend biomedicine and biomedical informatics during his tenure as NLM's director. The latter efforts are detailed in the first three sections of this book and in the last section of this chapter.

Don's personal annotations fill his copy of Norbert Wiener's *The Human Use of Human Beings: Cybernetics and Society* [25]*.* In the book, Weiner suggests information technology is an extension of human intelligence. The book advances one of Don's core tenets regarding a computer's capacity to replace human judgment. Don often said the question is not whether computers can reason or create better than a human. To him (and to Wiener), the question was whether computers and a human do better than a person alone.

Yet, the extent of his underlining and accompanying notes suggest Don paid similar attention to Mowshowitz's sharp and prescient criticism of information technology (IT) that was published in 1976 [26]. For example, in a double underlined passage, Mowshowitz writes: 'The information processing model of man presupposes the intertranslatability of all modalities of experience, their distinctive formative principles being submerged in universal computational practices. So, we will have computer art,

computer music, computer poetry, and what have you…' [26]. Mowshowitz adds: 'The computerized information processing system poses a challenge to the continued dominance of human intelligence in the control of human destiny' [26]. Don placed post-it notes in the book to get quick access to both quotes and frequently wrote notes to himself throughout the book (both a rarity). The Wiener and Mowshowitz's books are accompanied by other volumes that reflect a range of differing viewpoints about IT, its future, and its ultimate impact on socio-cultural progress.

Otherwise, the Lindberg library features a considerable collection (more than 100 books) devoted to the history of World War II. The World War II collection features eight books about Charles de Gaulle and several books on the life and political career of Winston Churchill. Many of the latter books contain descriptions of the persistent frictions between the two leaders. The World War II collection is supplemented by several books written by Churchill and there is a separate collection that focuses on other 18-20th century British history.

Don's interest in World War II is matched by his collection of books about the U.S. Civil War. There are 27 books about Civil War history on one shelf with a separate collection devoted to U.S. Presidents Lincoln and Grant.

The other U.S. presidents profiled in books within the Lindberg library include: Washington; Adams; Truman; Theodore Roosevelt; Franklin Delano Roosevelt; Clinton; and Obama. However, in terms of shelf space, no president compares to Thomas Jefferson. The Lindberg library includes a 20-volume collection of Jefferson's writings published in 1903 [27]. This is supplemented by shelves of books about Jefferson's life, ideas, and work in all of its diverse capacities. I recall how enthusiastic Don was when NLM's History of Medicine Division consulted with the staff at Monticello (Jefferson's home) about how to visually display historical eras and timelines for the Native Voices exhibition.

The Lindberg library's collection of American history overviews features books by Henry Steele Commager, an Amherst professor who Don knew and admired.

A collection of biographies about American technological leaders includes: several books about Thomas Edison; Walter Isaacson's books about innovators; as well as his biography of Steve Jobs [28].

Returning to Don's interest in indigenous Americans, the Lindberg library includes books about Native Americans, Native Hawaiians, and Alaska Natives. For example, the books about Native American history and culture collection includes the Chief Joseph collection. Most of the books about Alaska Natives focus on their history and culture. As aforementioned, the books about Native Hawaiian history and culture skew towards the contemporary and historic efforts to voyage the Pacific Ocean. These include Heyerdahl's books about ocean expeditions and more recent sea voyaging/navigation mentioned previously [29]. Several books are devoted to the tragic history of Kalaupapa, the 19th-21st colony for Hansen's disease patients on the Hawaiian island of Molokai [30]. Don interviewed providers and patients on site in 2011 with the able assistance of a NLM videographer crew for the Native Voices exhibition. The latter is mentioned in chapters within the current book [3].

Yet, in another interesting (and apparently premeditated) juxtaposition, the collection about indigenous Americans is coupled with many books about the building of the U.S. Southwest and the 'Manifest Destiny' era of American life and culture. This includes a collection of novels by Zane Grey.

In terms of literature, the Lindberg library includes the works of Kipling, Thoreau, Faulkner, Tolstoy, Hawthorne, Shakespeare, and Benet among others. The poetry

collection includes the works of Longfellow, Shelley, Dickinson, and Robert Frost (who Don met during his undergraduate days @ Amherst). While the Lindberg library emphasizes science and culture within the past two centuries, there is a collection of books about imperial Rome and ancient Greece.

Besides the arts, sciences, medicine, and culture, Don was interested in mass media practice and research. His collection about journalism and mass media includes books about Hearst, Sarnoff, Cronkite and by Lippmann, Friendly, Bradlee, Cronkite, Graham, Rooney, and Drew Pearson. (Don knew Drew Pearson, who is mentioned in the interview with Tyler Abell within the current book's memoirs, as well as Andy Rooney) [31].

The Lindberg library also features a complete collection of the books written by and about mass media scholar William Stephenson [32]. Stephenson, a faculty member in the Missouri School of Journalism in the 1960s-80s, was Dr. Lindberg's personal friend and colleague. Stephenson developed Q methodology, a mixed research method that enables an empirically grounded assessment of people's beliefs and attitudes (as opposed to the more conventional study of opinions). Q methodology influenced the development of psychographic analysis in advertising and strategic communication research.

For many years after Stephenson's death in 1989, Dr. Lindberg told me his awareness of the strengths and limitations of quantitative methods were influenced by Stephenson. Don hosted the annual research conference of the academic society that continues Stephenson's work @ NLM in 2007. During the conference, some NLM staff members who attended sessions frequently asked me: 'what does this have to do with bioinformatics or libraries?' I routinely responded: 'I promise you one thing; it all makes sense to Dr. Lindberg.'

The Lindberg home library also contains an array of books devoted to his hobbies, such as opera, classical music, art, photography, children's stories, as well as travel and culture.

The opera collection includes *The Verdi Companion*, and books about Madame Butterfly, Faust, Aida, 101 librettos, as well as biographies of divas and divos. These are accompanied by books that explore the impact of opera in society and culture. The classical music collection features several books about Mozart as a composer and a history of his life in Vienna. An often-perused three volumes of Shaw's music were placed near Don's desk so he could find them with a slight turn of his head to the left [33].

The Lindberg library includes books about the drawings/paintings and biographies of Matisse, Picasso, Renoir, and Norman Rockwell. (Don prized the Rockwell painting of small-town newsroom life that hangs in the National Press Club in downtown Washington and joked that seeing it was the best part of attending events there).

The Lindberg library contains a large collection (hundreds of books) about all aspects of photography. The books devoted to the work of specific photographers include: Karsh; Picker; Adams; the Westins (Brett and Edward); and Man Rey. There are books on photographic techniques, film developing, digital photo conversion, and the role of photography in society and culture. Don wrote more notes to himself within Susan Sontag's book about the cultural impact of photography than any I found within his library [34].

Two of the current book's memoirs note how much Don loved children's stories - and the Lindberg library has a sizable collection [35]. One of Don's favorites was an original edition of Mabie's *Fairy Tales Every Child Should Know* (published in 1910) and *Hero's Every Child Should Know* - and there are collections of children's stories from the U.S., England, Ireland, Scotland, Canada, France, Sweden, and Japan [36].

There are collections about some of Don's other hobbies such as boating and bird watching.

Regarding travel, the Lindberg library contains guides and other books about the history of Greece, Italy, Jerusalem, Heidelberg, Scotland, the Bahamas, Santa Fe, and New Mexico's pueblos. Despite Don's seven decades of international and domestic travel, the largest cluster of books about a nation's culture, traditions, heritage, and history focus on Japan. Japan is one of the few destinations where used guidebooks were shelved. Don indirectly noted the Japanese influence on him once after finishing a series of exasperating meetings with peers from other U.S. federal health agencies. Knowing I sensed his funk following the experience, Don shook his head and said: 'sometimes, it helps to appreciate the Kubuki theater.' Incidentally, one well-worn guidebook is about Brooklyn, his hometown.

A few tidbits: I found the books Dr. Lindberg authored/edited on the bottom shelf of the last bookcase located on the least accessible side of his study. A few others are randomly scattered - and none receive prominent shelf space. The barely noticeable inclusion of *his* books suggests Don's process of self-discovery occurred by reading about *other* people, places, eras, and topics. The Lindberg library's raison d'être was not to rediscover his own work.

Some final thoughts: Don turned to books to help him stay abreast of science, biomedicine, and technological as well as a range of other domains. Simultaneously, Don embraced books that challenged conventional wisdom and added insights about the roles of science, medicine, bioinformatics, higher education, and the humanities in fostering or undermining social progress. Don was not one-dimensional in his reading; he read to supplement what he knew and challenge what he believed. Unlike most collections I have seen, the Lindberg library reflects more than disparate books about hobbies and professional interests. Books helped Don grow intellectually and served as a reservoir to ward off cognitive dissonance, or the tendency of some leaders to discredit conflicting evidence, reject contrary opinions, and reinforce what they believe [37]. In fact, some of the books Don collected noted the risks embedded in the latter character trait among leaders.

Overall, the Lindberg library was a foundation of Don's ability to lead, understand, contextualize, and renew. His reading was integral to the leadership traits discussed below.

4. Dr. Lindberg's Leadership Traits – Cultivate Discovery and Innovation

Building on the Lindberg library as a managerial reservoir, the chapter discusses two of Dr. Lindberg's leadership traits: the cultivation of discovery and innovation by administrators and the need for leaders to contemplate and act in the greater public interest.

Previously, I explained Dr. Lindberg's rare ability to breakdown his administrative vision into a series of specific projects [38]. Don could deconstruct macroscopic ideas into well-defined projects and implement them in a stepwise manner, which I suggested is a rare skill and was a key to his administrative success. As I wrote in 2019, visionaries are rarely adept at implementation and implementors are infrequently proficient at social and professional vision. Don could do both [38].

That said, the emphases here are two other traits that defined Don's NLM leadership, which may have been inspired by some of the aforementioned books in his library. This section begins with Don's interest in cultivating self-discovery and innovation. The next section is devoted to a discussion of his interest to act in the public interest.

I readily acknowledge that Don rarely discussed his managerial philosophy in public and to the best of my knowledge, he did not write about the topics covered in the remainder of this chapter. As a result, my comments and impressions are derived from the times he shared some of his ideas and thoughts in personal conversations. I also draw inferences from the books in the Lindberg library.

Perhaps the conversation where I learned the most about Don's philosophy about encouraging individual discovery and innovative research were his reactions to a meeting with a senior administrator at a large public U.S. university.

Towards the end of his NLM helm, Don and I were invited to speak to different schools within a university on the same day - and spend some time with a senior administrator. We looked forward to the trip because the senior administrator was early in his/her post and sought our feedback regarding the university's long range institutional plans. Don and I shared a prior interest in - and knowledge about - the university.

To provide some background, the senior administrator's career was exemplary; he/she was a productive scientist with often cited academic publications; an excellent track record of receiving sizeable grants and contracts; significant international scientific board service; and successful graduate student mentoring. The administrator had overseen an impressive increase in grants and contracts, overall fund raising, student enrollment, and international research recognition at a different Research 1 university. (Research 1 is a term that describes U.S. higher educational institutions that receive significantly more research grants and contracts than peer universities). Don knew the administrator slightly from participation in scientific societies.

I emphasize we approached our individual meetings with a genuine interest in the administrator's plans and success. Don and I agreed to exchange reactions the morning after our separate visits.

At breakfast, Don and I shared our impressions with sadness and dismay. Although the senior administrator was interpersonally collegial, he/she failed to comment favorably about anyone within the university's current academic leadership. In each of our separate conversations, the senior administrator refused to compliment or support the work of a dean, an individual faculty member, staff member, student, or even prominent alumni. Instead, the administrator sharply criticized some of the university's other leaders and researchers and discussed the superiority of colleagues at prior institutions - all without prompting to do so. I told Don with some astonishment, 'I did not hear one nice word about *anyone* (at the current University).'

I added that I looked at PubMed, Google Scholar, nsf.gov, report.nih.gov, and a few other indexing services and found the University's recent track record of publications and grants seemed to challenge some of the senior administrator's claims.

In one of the rare times I ever heard Don deliver a soliloquy about leadership, he responded: 'The place is dying. A University (or *any* educational institution) cannot succeed if its leaders denigrate productive people. Instead, the boss needs to cultivate and appreciate. What bothers me is how (he/she) could forget this….'

Before he half-finished a glass of orange juice, Don explained the best way to manage a large educational institution was to cultivate employee discovery, provide the degrees of freedom talented people need to succeed, show interest but avoid micro-management, and then, support as well as salute the ensuing efforts. 'You need to let

people know you have their back to offset the criticisms that creative people often receive for their efforts,' he exclaimed.

Then, Don noted the need to provide research autonomy and degrees of freedom with support and without micro-management was especially important at the National Institutes of Health (NIH). Don explained NIH researchers were subject to comparatively strict mandates to deter employee conflict of interest. He continued that unlike university faculty, some top NIH researchers received annual third-party reviews of their external professional and community activities as well as their investments. In addition, Don noted NLM (similar to all NIH institutes) also required internal review prior to the refereed publication and conference submission of employee research. Since some of the latter requirements did not exist in research universities, Don remarked NIH's added burdens (coupled with comparatively less employee governance in the federal government) needed to be addressed by carefully creating a conducive atmosphere to support innovation and research.

Don explained an encouraging atmosphere partially was advanced by a series of strategies. Among other efforts these included: giving individuals sufficient time to conduct research; reducing non-research distractions; providing internal funds to support research; encouraging employee professional development; supporting travel to refereed conference presentation; encouraging expert collaboration and the diffusion of findings; hiring post-doctoral and other research fellows; bringing stimulating scholars to speak at NLM; and when possible, creating a family-like atmosphere. While these strategies may have been implemented differently within NLM's divisions, the chapters in the first three sections of this book attest that Don often succeeded in creating an institutional climate that supported individual and collaborative research, discovery, and innovation.

The chapters in the first three sections of this book (and the memoirs in this section by George Thoma, Randolph Miller, Rashid Bashshur, and Tom West) also suggest NLM developed an ethos during Don's watch that was guided by a sense of purpose to serve health care providers and later the public; develop fields (such as biomedical informatics and medical libraries); support intramural and extramural research; and even induce a positive social climate for collaboration and morale by hosting periodic dinners and events [39].

The chapters in the book's first three sections (and the aforementioned memoirs) add that NLM often was willing to advance technical innovation and stay ahead of the curve set by industry, universities, medical schools, and the federal government. The chapters note researchers intramurally and externally supported by NLM perceived they worked for an educational institution that was willing to lead to advance ideas while remaining mindful of the immediate and long-range interests of medical professionals, librarians, and eventually, the public. The chapters suggest NLM created an esprit de corps based on its supportive attitudes about research and researchers and a personal touch that included a genuine interest in a person's research and welfare, which were hallmarks of Don's administration and leadership.

Returning to the Lindberg library, many of the aforementioned books on the history of science and medicine directly or indirectly address how scientific and technological research thrives (or is compromised). Especially in *The Ascent of Man*, Bronowski noted that similar to the arts, science flourishes in an atmosphere where individual degrees of freedom, individual discovery, tolerance and diffusion are omnipresent [21]. Other authors, such as Dubos, make similar points, which are reinforced by books about the history of science's progress that were part of Don's collection [22]. While the latter books do not address administrative leadership, most embed counsel that scholarship is

associated with a prevailing atmosphere that encourages academic values of independence, freedom to take risks, an ongoing curiosity, and an emphasis to support research activities.

I suggest Don's attitudes about good management were grounded in the latter values, which engendered a defining leadership trait.

Incidentally, while there was no record of campus unrest at the time of our meetings, Don gave the senior administrator 18 months before deans and senior faculty would demand an ouster. I was more pessimistic and predicted a change would happen within a year.

We were both wrong. The dismissal occurred seven months later - and was led by a coalition of deans, faculty, and students who represented all of the university's academic divisions. Three years after the breakfast, in a return to discuss our experience with the senior administrator, Don summarized: '(he/she) forgot about the need to support people, validate their curiosity, as well as the importance to create a vibrant institutional personality. The latter impacts morale and the zest with which people work, support others and the institution itself.'

5. Stewardship, Education, Media, and a Public Interest Compass

A related trait that impacted NLM's morale and characterized Don's leadership was his determination to act in the greater public interest and his commitment to use the Internet/World Wide Web for educational purposes. This section covers some of the origins and influences of Don's internal compass to act in the greater public interest in making administrative decisions.

To backup momentarily, I was a health-science journalist and launching a second career as a journalism professor/mass communication researcher when I met Don in 1977. For the next 42 years, we often discussed the leadership of journalists who balanced stakeholder versus the public interest (regardless of the policy issue at hand), the socio-cultural impact of mass media platforms, and the social responsibilities of the stewards of a new mass communication's medium (the Internet coupled with the World Wide Web). Don preferred to discuss the latter topics more than immediate issues of the day, our reactions to local, national, or international news, the actions of other leaders in government and industry, or personal matters. He joked that he could discuss biomedical informatics and clinical practice issues with the rest of his colleagues. Let's call it a dangling conversation that spanned five decades.

I was not surprised when my 2020 tour of the Lindberg library found books about journalism that discussed the profession's social responsibilities and profiled journalistic leadership as well as books and papers about the social impact of mass media and information technology. I introduced some of these books in this chapter's second section and will revisit a few of them here.

Indeed, the book *Public Opinion* by Walter Lippmann (published in 1922) is an enduring primer on public leadership and the advantages versus occasional risks of making decisions based on the greater public versus parochial interests [40]. Lippmann suggests a primary social responsibility of journalists (and leaders in any profession) is to balance stakeholder interests with broader public concerns. Lippmann suggests leaders should advance corrective action when decisions that impact communities, societies, and culture are grounded in more parochial than public concerns. The books about 20th and

21st century journalists that Don collected indirectly assess their leadership through Lippmann's framework. The biographies by or about Pearson, Bradlee, Friendly, Rooney, and Cronkite in the Lindberg library suggest how each responded to events and disclosed how stakeholders used power and influence to undermine, ignore, or advance the rights and concerns of most citizens [31]. The books note how these journalists saw their profession and job as an opportunity to lead by expanding social awareness and constructively influence public opinion.

Unsurprisingly, Don enjoyed conversations about news editors who sacrificed subscribers and revenues to pursue stories of community importance. Don especially liked hearing about John Seigenthaler and Gene Patterson, 20th century U.S. journalism icons, who were the first news executives in Southern cities to lead a news organization's coverage of civil rights, race, and socio-economic disparities despite persistent and sometimes vitriolic community criticism or disinterest.

Yet I suggest Don's interest about journalism in conversations and books was to supplement leadership profiles about persons with the social awareness and dedication to act in the public interest - and the courage to commit despite socio-professional pressure and reproach. A similar leadership narrative undergirds some of the books he collected about American presidents, British prime ministers, and military decision-makers during the U.S. Civil War. In contrast, some of the books he collected about Native Americans provide a counter narrative about the impact of leaders who lacked an awareness of humanitarian principles and made decisions based on more parochial interests.

Since the publication dates of the array of books about public leadership in the Lindberg library spans more than 60 years, the timeline (and the condition of the books on his shelves) suggests Don developed an interest in management within the public interest long before he became NLM's director in 1984.

Meanwhile, I suggest the following series of ideas - coupled with an opportunity to lead a federal health agency - combined to generate a sense of vision, purpose, and commitment, which became a foundation of Don's NLM leadership from 1984-2015.

By the mid-1970s Don had written about the potential of computers and information technology to impact medical research, medical knowledge, and medical practice [41]. As some other chapters in this book describe, Don was among the first to recognize that the diffusion of computing would have a transformative impact on medical professionals. However, these insights were just the start of his exposure to some related and transformative ideas that he began to consider.

For example, the books in the Lindberg library by Weiner and Mowshowitz (published in the mid-1970s) expanded the scope of the professional impact of computing to professions outside of science and medicine and noted the impact of the diffusion of computing on society and culture [25-26]. While the projected impact on major professions, society, culture, and science was perceived dissimilarly by Weiner and Mowshowitz, both books advanced the idea that information technology would impact the future of most aspects of human endeavors. As I mentioned previously, Don took notes and scribbled ideas in the margins and any available white space in the Weiner and Mowshowitz books, which suggests he was impressed by both. I suggest these and other writings (especially from Daniel Bell) broadened Don's perspective about the social and professional impact of computing. Don began to appreciate that the socio-cultural impact of information technology was significantly more expansive than its bearing upon medical practice, research, and knowledge (which he previously described).

Then, as Don began to ponder the wider social impact of IT, he was exposed for the first time to books and ideas about the long-term socio-cultural impact of mass media platforms on society. I am aware of the latter development because the topic was the basis of many conversations for more than four decades. Especially from 1978 to the mid-1980s, I was invited to lunch to discuss Innis, McLuhan, Carey, and Stephenson more than other professional or personal issues. Briefly, the Innis, McLuhan, and Carey thesis is the socio-cultural impact of public exposure to a mass media channel (such as print-based, audio-based, or video-based media) is far more profound than the content each medium provides. Innis, McLuhan, and Carey's ideas impressed Don, who found their implications intellectually compelling [42].

Since most of this book's readers do not have a mass communication research background, I will mention a little more about the core ideas that Don and I discussed because I believe they impacted his professional vision. I should add Don's initial interest in reading about the socio-cultural impact of mass media channels and platforms was inspired by his friend and colleague William Stephenson, whose scholarship touched on similar issues [32].

More specifically, Innis proposed changes in mass mediums or platforms from chiseled words to papyrus, hand-set, the Gutenberg press, linotype and mass-produced books and periodicals impacted pre-20th century society and culture more profoundly than the messages these printed and text-oriented mass mediums afforded [42]. Innis also noted the significant socio-economic, political, and cultural differences that occurred once societies transitioned from an oral to a written tradition as a primary means of mass communication and social learning.

I remember how interested Don was when he read McLuhan's interpretation of the social impact of television's introduction (as a mass medium or platform) because Innis provided a context to understand McLuhan's ideas. During the time he read both authors, Don mentioned he began to understand McLuhan's core arguments by contrasting the differences in how medical students raised during the television era learned compared to the pre-television generation. He often said to me that it was especially challenging to teach contemporary medical students because they learned more visually than their predecessors (which included his generation). 'I did not realize how confounding a challenge the radio generation (that Don experienced) must have been to my instructors.'

An essay by media scholar James Carey about the similarities and differences between Innis' and McLuhan's ideas prompted Don to exclaim for the first time in the early 1980s: 'I'm starting to appreciate that in the long run the (mass) medium *may be* the message [42].'

At this time, Don read a second essay from Carey that assessed the socio-cultural impact of the telegraph's introduction starting in 1848 [43]. Carey explains how the telegraph's unprecedented capacity to decode and transmit information did much more than enable 19th century U.S. military commanders to stay in touch with presidents and send reports about news across town or to different cities (that prompted the parallel launch of the Associated Press). Carey explains that during its heyday as a technological innovation, the telegraph transformed how people perceived time and physical/geographical distance.

After reading Carey's essay, Don told me he interpreted it as suggesting how some of the major historical and geopolitical events from the mid-19th through the early 20th century, such as wars and international colonialism, were impacted by the launch of a seemingly innocuous encode/decode technology, which accelerated the capability to efficiently exercise administrative control from a great distance.

In turn, it did not take long for Don's new interest in the impact of mass media platforms to transform into a deeper understanding, enthusiasm, and accompanying concern about the growth of personal computing, networked computing, and the possibility of future public access to then-experimental World Wide Web. In conversations in the early 1980s, Don began to describe the convergence of personal computing, networked computers, and the then-hypothetical publicly accessible Web as a once in a lifetime opportunity - with an accompanying set of social responsibilities. 'Perhaps this time some leaders can get ahead of the curve,' he mentioned more than once.

In conversations, Don demonstrated his fresh understanding by questioning why some news organizations were interested in selling their news archives at a time when the then-experimental Web raised the unprecedented possibility for readers to have access to present combined with past news via then-nascent home and office desktop computers. He asked: 'Don't they (news executives) grasp what is coming?' Of course, the fact Don raised the question suggested he did….

Don also began to discuss the broader responsibilities, and the rare prospects, for persons in a position of leadership to recognize the implications of the birth and diffusion of a new mass communication's medium. 'Its best public use would be for educational purposes,' he said. 'Let's hope some leaders see the opportunity to establish an educational course before the new media's future as a profit center becomes evident....'

So, it was with historically significant timing (as fate may have it), that Don was appointed as NLM's director in 1984. Don's appointment occurred at the same time his understanding of mass media, information technology, and the need for leadership and stewardship were stimulated by a convergence of ideas and transformative events. Desktop and personal computers were starting to thrive, a new era of networked computing and connectivity was emerging, and the potential loomed for the experimental Internet and Web to provide much more than text and data.

Fortunately for Don, NLM already had an educational mission. NLM was committed to the collection and provision of medical information and literature mostly to healthcare providers via print and customer service platforms that served and collaborated with libraries and medical publishers across the U.S. and internationally. Additional interest was established in the use of innovative information technology to advance NLM's mission. Indeed, Don was one of the biomedical informatics' pioneers whom NLM supported. The challenge was to generate a sense of vision, purpose, and commitment regarding the use of new media technologies to assist medical professionals and concurrently, demonstrate how a new mass media platform could be put to its optimal public use.

A few weeks before Don officially became NLM's director an excited William Stephenson told me: 'now, we are really going to see something. Lindberg understands a new mass medium is emerging, its potential for educational purposes, and he will be in charge of a national health information institution with educational values. The synergy and timing could not be better.'

In terms of stewardship, Don brought to his new job the key understanding that mass media were an extension of human activity that could be put to their best use by enabling social and professional progress More specifically, Don understood a new mass medium's and emerging information technology's best uses were for educational purposes to: a) transform the ability of providers to obtain evidence-based medical information and b) organize health information so it could be optimized and accessed by

utilizing a platform that enabled the transmission of data, text, photos, audio, video, data sets, with search capabilities (for the first time).

With this embedded context, the diverse and multidimensional projects described in this book are consistent with a larger educational, public, and professional service vision. The development of: *MEDLINE; PubMed; PubMed Central; Clinicaltrials.gov, MedlinePlus.gov; UMLS; PubChem; Genetics Home Reference; Entrez; GenBank; NCBI Blast; Hazardous Substances Data Bank; Toxicology Data Network*; support for electronic health records, expert systems, machine learning, medical libraries, and High-Performance Computing and Communications; *the Visible Human; Turning the Pages*; as well as other information resources/services, other genetic surveillance platforms; outreach and educational programs for scientists, scientists, and the public are elements and extensions of a lofty plan.

The perseverance and mettle Don demonstrated by his support for NLM's educational projects and maximal public and professional access despite criticisms by diverse health care stakeholders (which is mentioned in several chapters in this book) suggest his commitment to educational values (based on the greater public interest) and the need to be a pioneering steward of a federal health agency and a new mass medium [44].

Don's challenge was to operationalize his vision, which began on the day of his appointment as NLM's director in a speech that set an agenda for the Library's immediate and long-range future [45]. Remarkably, Don remained focused on the optimal use of NLM's resources for educational and leadership purposes for the next 31 years. While it helped that Don had the simultaneous ability to perceive the forest, its trees and leaves, I suggest he would assert most of NLM's accomplishments were the result of the efforts of the Library's staff coupled with the evolution of research in biomedical informatics and associated scientific disciplines - with the cooperation of NLM's consultants and stakeholders.

I should add Don drew inspiration, guidance, and perhaps an ethical compass from Secretary John W. Gardner, U.S. Department of Health, Education and Welfare in the mid-1960s, who explained the differences between leadership and stewardship and implored persons in federal leadership to foster a more just society, promulgate educational values, act in the public's best interest, and remain tolerant of criticism and new ideas [46]. Don underlined many sections in Gardner's book about governance including this one: 'We don't need leaders to tell us what to do. That's not the American style of leadership in any case. We do need men and women in every community in the land who will accept a special responsibility to advance the public interest, root out corruption, combat injustice and care about the continued vitality of this land' [46, p. 134].

Otherwise, the current book attests how Don's leadership fostered an ethos that inspired many both inside and outside of NLM. I suggest his acumen was grounded by a converged vision that was sustained and cultivated by the ideas he gained from immediate colleagues as well as the authors and books that influenced him, which were parked on the ground floor of his personal library. It is a remarkable legacy I am grateful to recount.

Acknowledgement

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Resources About
Donald A.B. Lindberg M.D.

Robert A. LOGAN Ph.D.[1]
U.S. National Library of Medicine (retired)

1. Introduction

This section provides a selected, partially annotated guide to Internet-based and other resources about Donald A. B. Lindberg M.D.'s contributions and career. The criteria for selections include an active URL, a distinctive approach, and recommendations from some of the book's contributors. Its sections provide some tributes written after Dr. Lindberg's death, selected obituaries, tributes delivered when Dr. Lindberg's retired from the U.S. National Library of Medicine (NLM), links to the Native Voices exhibition, other resources about Dr. Lindberg's career and contributions, manuscripts authored by Dr. Lindberg, manuscripts about biomedical informatics' progress co-authored by Dr. Lindberg, and links to NLM annual reports written during Dr. Lindberg's helm.

2. Selected Tributes and Obituaries Written after Dr. Lindberg's Death in August 2019

Kohane I, Berg JM. Donald A.B. Lindberg (1933-2019). Science. 366:6461, p. 37. DOI: 10.1126/science.aaz3644.
https://science.sciencemag.org/content/366/6461/37
This tribute in *Science* provides information about Dr. Lindberg's biomedical contributions and suggests he was an 'unsung hero of medical research and science.'

Humphreys BL, Rosenbloom M. Donald A.B. Lindberg, MD, honorary MLA member. J Med Libr Assoc. 2020, Apr:108(2): 314-317.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7069826/;
http://jmla.mlanet.org/ojs/jmla/article/view/878/1083
Humphreys was NLM's Deputy Director from 2005-2015 and NLM's acting director from 2015-2016. Humphreys is a co-editor of the current book.

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Kulikowski CM. Donald A.B. Lindberg's historical impact: catalyzing the revolution in biomedical and healthcare knowledge through informatics with free, open dissemination worldwide. Yearb Med Inform 2020. P. 203-207. http://dx.doi.org/10/1055/s-0040-1701972

Dr. Kulikowski, who is a contributor to the current book, summarizes Dr. Lindberg's contributions to biomedical informatics and healthcare knowledge.

McCray AT, Haux R, van Bemmel JH. In memorium: Donald A. B. Lindberg (1933-2019). Methods Inf Med 2019: 58:107-108. https://doi.org/ 10.1055/s-0039-3400249.

This tribute provides a brief overview of Dr. Lindberg's contributions to medical libraries, science, biomedicine, and biomedical informatics. Dr. McCray was the director of the Lister Hill National Center for Biomedical Communications and worked with Dr. Lindberg at NLM for almost two decades. Dr. van Bemmel is a contributor to the current book.

Logan RA. Remembering Don Lindberg: a transformative leader. Health Affairs Blog. Sept. 27, 2019. https://www.healthaffairs.org/do/10.1377/hblog20190923.307979/full/

This tribute focuses on Dr. Lindberg's character and leadership qualities. Logan was a member of NLM's senior staff from 2006-2018 and is one of the current book's co-editors.

Seelye KQ. Dr. Donald Lindberg, 85, dies: opened medical research to the world. New York Times. September 2, 2019. https://www.nytimes.com/2019/09/02/obituaries/dr-donald-lindberg-dead.html?searchResultPosition=1

The New York *Times'* obituary is based on interviews with some colleagues and members of the Lindberg family. It is reprinted with an introduction from Elliot Siegel (one of the current book's co-editors) in: Information Services & Use 39 (2019) 123–126. DOI:10.3233/ISU-190058.

Donald A.B. Lindberg, pioneer in medical informatics, died Aug. 17, 2019. Columbia *Missourian*. August 21, 2019. https://www.columbiamissourian.com/obituaries/family_obituary/donald-a-b-lindberg-pioneer-in-medical-informatics-died-aug-17-2019/article_022ee246-c45b-11e9-964f-47c2551d9b1c.html

This is a conventional obituary about Dr. Lindberg's life and career. The Columbia *Missourian* is a daily metropolitan newspaper published by the University of Missouri-Columbia School of Journalism. Dr. Lindberg lived in Columbia, MO and was a faculty member at the University of Missouri-Columbia School of Medicine for almost two decades.

3. Some Tributes from Dr. Lindberg's NLM Retirement in March 2015

https://www.nlm.nih.gov/news/DrLindbergRetirementSymposiumVideos.html#fairwinds_title

Includes one hour and 45 minutes of video tributes to Dr. Lindberg. The videos were prepared by NLM for Dr. Lindberg's retirement ceremony on March 30, 2015.

https://collections.nlm.nih.gov/catalog/nlm:nlmuid-101629547-vid
    Provides Dr. Lindberg's speech at the ceremony where he was sworn-in as NLM's director on October 11, 1984. It outlines part of the path and steps he would take for the next 31 years.

https://wayback.archive-it.org/org-350/20180911191348/https://www.nlm.nih.gov/news/bor_resolution_lindberg_2015.html
    This 2015 resolution from the NLM Board of Regents outlines some of Dr. Lindberg's contributions to NLM and biomedical informatics.

https://infocus.nlm.nih.gov/2015/04/14/the-end-of-an-era-director-lindberg-retires-after-31-years-leading-nlm/
    NLM's *In Focus* report on Dr. Lindberg's retirement ceremony.

4. Links to Native Voices: Native People's Concepts of Health and Illness

https://www.nlm.nih.gov/nativevoices/index.html
    This is the home page of *Native Voices*, which included exhibitions, websites, video interviews, art, resources, and much more. The development and contributions of *Native Voices* are described in two chapters in section four of the current book.

https://nvinterviews.nlm.nih.gov/interviews//
    Dr. Lindberg interviewed more than 100 Native American, Alaska Native, and Native Hawaiian physicians, other health care providers, faculty, traditional healers, clergy, hospital/organizational administrators, medical and public health students, political leaders, and others, for the *Native Voices* exhibition. The interviews are available here.

5. Links to Other Written Resources about Dr. Lindberg's Career and Contributions

https://lhncbc.nlm.nih.gov/system/files/Medical-Informatics-Pioneers_Oral-History_DONALD-LINDBERG_2015-09-04_web.pdf
    This oral history about Dr. Lindberg was prepared by NLM's Lister Hill National Center for Biomedical Communication in 2005.

https://www.mlanet.org/blog/lindberg-donald-ab-md
    Provides a brief oral history of Dr. Lindberg's tenure at NLM from the Medical Library Association. It was prepared in 2015.

https://en.wikipedia.org/wiki/Donald_A._B._Lindberg
    This accesses Wikipedia's page about Dr. Lindberg.

Wortsman P. A digital pioneer at the National Library of Medicine: Donald A.B. Lindberg, 58'. In: Wortsman P. The caring heirs of Doctor Samuel Bard: profiles of

selected distinguished graduates of Columbia University Vagelos College of Physicians and Surgeons. New York: Columbia University Press; 2019. p. 239-244.

This profile covers some aspects of Dr. Lindberg's career, influences, and contributions. It is included in a book of tributes to Samuel Bard M.D., Columbia University, who was one of Dr. Lindberg's mentors.

Smith KA. Laws, leaders, and legends of the modern National Library of Medicine. J Med Libr Assoc. 2008 Apr;96(2):121-33. DOI: 10.3163/1536-5050.96.2.121. PMID: 18379667; PMCID: PMC2268223. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2268223/

This paper explains how four Congressional actions from 1956 to 1988 impacted NLM's growth and development. While the paper covers actions prior to Dr. Lindberg's tenure as NLM's director, it notes how Dr. Lindberg envisioned a new role for NLM in advancing biomedical informatics when he became NLM's director in 1984. The latter resulted a 1986 long range plan that provided a foundation for the congressional legislation which created the National Center for Biotechnology Information (NCBI). It is written by Kent Smith, NLM's Deputy Director from 1979-2004, who is an author of a chapter in the current book.

6. Manuscripts Authored by Dr. Lindberg

There are two ways to access the research and writings of Dr. Lindberg in PubMed. PubMed, developed by NCBI, became the interface to NLM's MEDLINE database and other journal and book chapter citations while Dr. Lindberg was NLM's director. NCBI is a division within NLM.

https://pubmed.ncbi.nlm.nih.gov/?term=Lindberg%20DA
Or, type 'Lindberg DA' in the search box on PubMed's home page: https://pubmed.ncbi.nlm.nih.gov

https://wayback.archive-it.org/org-350/20190104163823/
https://www.nlm.nih.gov/pubs/staffpubs/od/dablbib.html
Provides an archive of some of Dr. Lindberg's work at NLM.

https://scholar.google.com/
Dr. Lindberg's writing also is accessible through Google Scholar. Type 'Donald AB Lindberg' in the search box.

7. Summaries of Biomedical Informatics Progress and Access to Biomedical Information: Co-written by Dr. Lindberg During his Tenure as NLM's director

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2441483/
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5171500/
These articles, co-authored by Dr. Lindberg and Betsy Humphreys in 2008 and 2016, provide overviews of the progress in biomedical informatics.

8. Links to NLM Reports during Dr. Lindberg's Tenure as Director

NLM annual reports from 1984-1996.
https://www.nlm.nih.gov/hmd/manuscripts/nlmarchives/annualreport.html
     These reports cover the first 12 years Dr. Lindberg was NLM's director.

NLM annual reports from 1997-2015.
https://www.nlm.nih.gov/pubs/reports.html
     These reports cover the 18 additional years Dr. Lindberg was NLM's director. The link also provides access to diverse NLM reports, which include several written during Dr. Lindberg's tenure.

https://www.nlm.nih.gov/od/bor/bor.html
     Minutes of NLM's Board of Regents meetings during the years Dr. Lindberg was NLM's director (1984-2015).

NLM News
https://www.google.com/books/edition/News/TVYf-ohKmgMC?hl=en&kptab=editions
     Digitized versions of *NLM News*, which cover a range of information about some of NLM's grant programs, outreach activities, developments at NCBI, milestones related to NLM services for consumers, and other initiatives during Dr. Lindberg's helm.

Acknowledgements

Don Lindberg: A Photographic Legacy

Robert A. LOGAN Ph.D. [a,1] and Mary M. LINDBERG R.N. [b]

[a] *U.S. National Library of Medicine (Retired)*
[b] *Montgomery Hospice Home Care Volunteer*

Abstract. Donald A.B. Lindberg M.D. was an enthusiastic photographer. This chapter presents five photographs that had special meaning to him. They are accompanied by five pictures taken of him by other photographers. The captions explain a little about each image.

Keywords**.** Donald A.B. Lindberg M.D., photographs

1. Five Photographs Taken by Donald A.B. Lindberg M.D.

Picture 1. These water lilies were either near Williamsburg, VA or Columbia, MO. Dr. Lindberg sometimes wished there were more ponds with water lilies to photograph near his Maryland home. Photo: courtesy of Mary Lindberg.

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Picture 2. This photo of Martin Lindberg (Dr. Lindberg's grandson) was taken just as Martin discovered parrots could talk. The setting was in Provincetown, MA. circa 2002 when Martin was six years old. Dr. Lindberg waited until the sun popped through a cloud to snap the picture. The book's cover is a photo of Martin with his grandfather and Martin also provides a memoir in the current book. Photo: courtesy of Mary Lindberg.
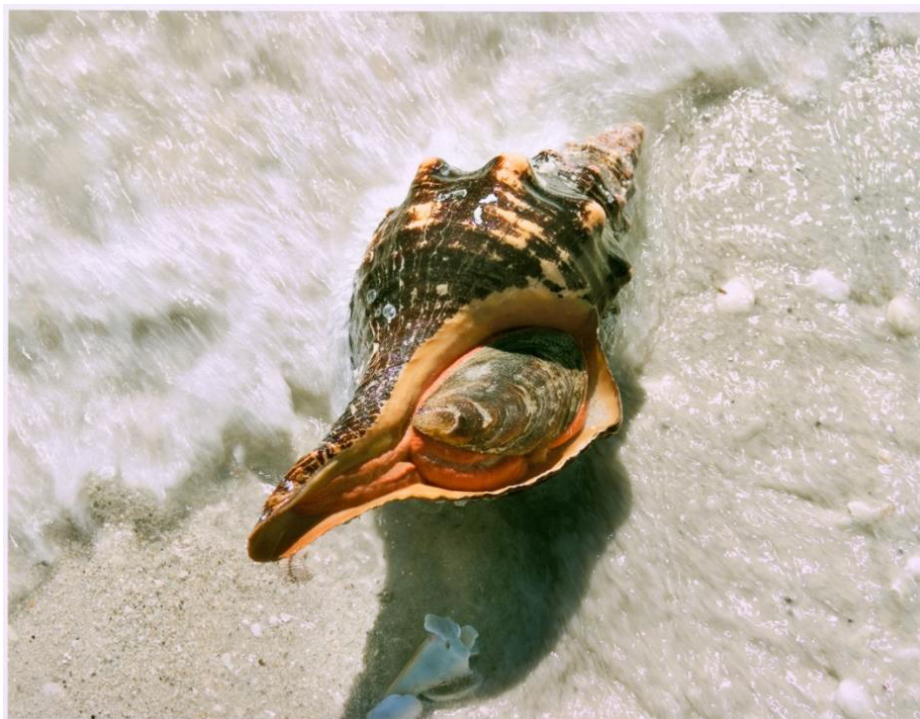
Picture 3. This photo of a quohog was taken on a beach on Little Gasparilla Island in Florida. The photo shows the quohog's operculum. Dr. Lindberg and the Lindberg family enjoyed visiting this area. Photo: courtesy of Mary Lindberg.

Picture 4. The bird on the left is a blue footed booby accompanied by friendly pelican in the Galapagos Islands in 2010. Dr. Lindberg later took several photos of the booby's stellar efforts to protect an egg from local sun and heat on nearby sand. During the same trip, a small seal happily accompanied Mary Lindberg as she went for a stroll on a beach. Photo: courtesy of Mary Lindberg.

Picture 5. Jon Lindberg (Dr. Lindberg's son) carefully holds Frances Lindberg (Dr. Lindberg's granddaughter) following successful emergency surgery on the date of her birth, September 1, 2004. A photo of Dr. Lindberg with Jon when he was a boy is in the next section (see Figure 9). Photo: courtesy of Mary Lindberg.

2. Five Photographs Taken of Donald A.B. Lindberg M.D.

Picture 6. Dr. Lindberg and Mary Lindberg pose in front of their portrait at its unveiling in 2015. The artist is Bradley Stevens. While the photo is reproduced in black and white, Mary Lindberg wears a red suit in the portrait. Betsy Humphreys advised Mary to wear red because: 'all NLM's portraits are of men in dark suits.' Mary Lindberg reports Stevens mostly painted from photographs and did not require long poses. The Lindberg portrait is on display at the U.S. National Library of Medicine (NLM). Photo: courtesy of Rob Logan.
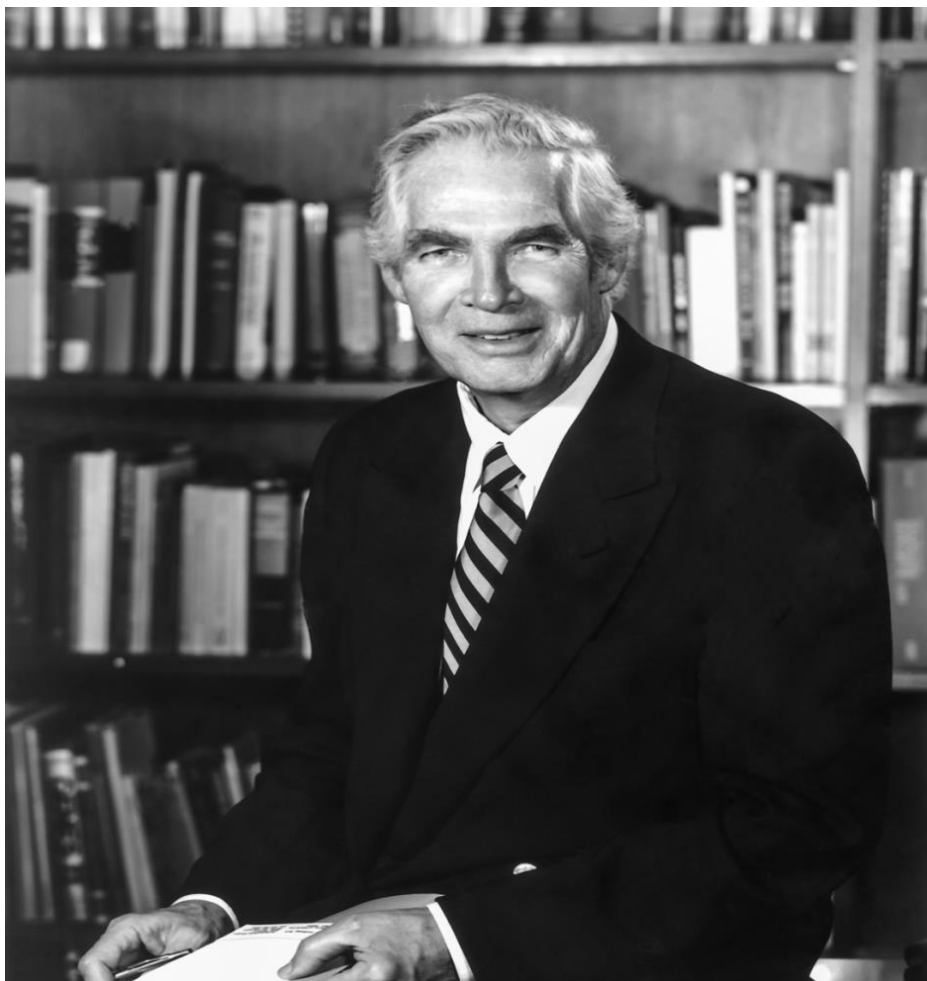
Picture 7. Dr. Lindberg in his office circa 2002. This is one of several official photographs that were distributed by the U.S. National Library of Medicine at the time. Photo: courtesy of NLM.

Picture 8. Dr. Lindberg speaks in Seattle, WA. in 2011 to launch the cross-country journey of the healing totem pole carved by the Lummi Nation (from the U.S. state of Washington). The healing totem pole celebrated the opening of the National Library of Medicine's Native Voices: Native People's Concepts of Health, Wellness, and Illness exhibition. The healing totem pole proudly still stands in front of NLM. Photo: courtesy of Rob Logan.

Picture 9. Dr. Lindberg and Mary Lindberg attend a festschrift for Stanford University Professor Edward Feigenbaum Ph.D. The picture was taken at a Chinese restaurant in Palo Alto, CA. circa 2006. Photo: courtesy of Dr. Ted Shortliffe.

Picture 10. Dr. Lindberg talks to his son Jon, age 7, on a semi-flat rock during a break at a medical conference in Aspen, CO. Dr. Lindberg liked to bring his then-young sons to conferences and relished their time together. Note the semi-matching boots. Photo: courtesy of Mary Lindberg.

Author Index

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