Building better connections: the National Library of Medicine and public health

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Purpose: The paper describes the expansion of the public health programs and services of the National Library of Medicine (NLM) in the 1990s and provides the context in which NLM's public health outreach programs arose and exist today.

Brief Description: Although NLM has always had collections and services relevant to public health, the US public health workforce made relatively little use of the library's information services and programs in the twentieth century. In the 1990s, intensified emphases on outreach to health professionals, building national information infrastructure, and promoting health data standards provided NLM with new opportunities to reach the public health community. A seminal conference cosponsored by NLM in 1995 produced an agenda for improving public health access to and use of advanced information technology and electronic information services. NLM actively pursued this agenda by developing new services and outreach programs and promoting public health informatics initiatives.

Method: Historical analysis is presented.

Results/Outcome: NLM took advantage of a propitious environment to increase visibility and understanding of public health information challenges and opportunities. The library helped create partnerships that produced new information services, outreach initiatives, informatics innovations, and health data policies that benefit the public health workforce and the diverse populations it serves.

INTRODUCTION

Public health is concerned with improving the health of entire populations. It has been defined as encompassing ten essential services:

- monitoring health status to identify community health problems;
- diagnosing and investigating health problems and hazards in the community;
- informing, educating, and empowering people about health issues;
- mobilizing community partnerships to identify and solve health problems;
- developing policies and plans that support individual and community health efforts;
- enforcing laws and regulations that protect health and ensure safety;
- linking people to needed personal health services and assuring the provision of such services when otherwise unavailable;
- assuring a competent public health and personal health care workforce;
- evaluating the effectiveness, accessibility, and quality of personal and population-based health services; and
- research for new insights and innovative solutions to health problems [1].

By this or any other definition, the National Library of Medicine (NLM) is probably the largest public health library in the world. Public health has been a core subject for NLM at least since the 1860s when it was the Library of the Surgeon General’s Office, US Army. The NLM collection and bibliographic databases cover public health literature produced by mainstream publishers, US federal and state government agencies, and international organizations. The library has substantial, although less comprehensive, holdings of public health “gray literature” and modern manuscripts (i.e., the papers of individuals and organizations influential in the development of public health interventions and policy).

Since the mid-1960s, NLM’s toxicology and environmental health program has developed specialized bib-
liographic and data resources useful to public health workers focused on poison control, environmental monitoring, and public health emergencies that involve hazardous substances [2]. In the 1980s, the library developed special HIV/AIDS information services targeted at public health workers, community-based organizations, and the affected population [3]. Beginning in 1990, NLM's health services research information program developed new databases and services that were directly relevant to several core public health activities, including monitoring health status, health policy development, and evaluation of the effectiveness, accessibility, and quality of health services [4].

Potential relevance notwithstanding, in the second half of the twentieth century, the US public health workforce made relatively little use of NLM's information services and rarely applied for NLM funding [5] or training opportunities. This was not surprising as most public health workers lacked any connection to librarians [6], who have been instrumental in spreading awareness of and access to NLM services among other health professionals. In general, the public health workforce did not have the computers and telecommunications needed to use online services [7] and could not afford even modest fees for copies of documents or online searches. By the 1990s, recently graduated public health physicians and nurses would probably have learned about MEDLINE during their professional education, but most of the diverse public health workforce would not have been exposed to NLM services during their training. Relatively few public health workers have degrees in public health [8], and many schools of public health were slow to incorporate training in the use of online information services into their curricula [9]. Given the general lack of information technology infrastructure in the public health sector, it was not fertile ground for applications for NLM's information systems or informatics research grants. It was also true that NLM services and programs were not ideally suited to the reality of public health. The underlying factors that prevented any significant public health use of existing NLM services also prevented the library from receiving user feedback on ways to enhance its services to meet public health needs.

In the 1990s, a number of forces aligned to heighten concern about the poor state of public health access to information services and information technology and to provide NLM with new opportunities to connect with the public health community. This paper describes the broader context in which the library's expanded public health outreach programs arose and exist today. Table 1 provides a categorized timeline of many relevant events.

DEVELOPMENTS IN THE EARLY 1990s

Information outreach

In 1989, a special NLM Long Range Planning Panel chaired by Michael Debakey strongly recommended that NLM and the National Network of Libraries of Medicine (NN/LM) work to improve information access for “unaffiliated health professionals,” in other words, those who had no regular connection to an institution (hospital or academic center) that provided library services [10]. NLM received encouragement and $2 million in additional funding from Congress in fiscal year 1991 for such outreach, and the Regional Medical Libraries and other network members expanded efforts to reach physicians and nurses providing safety-net services in community clinics, as well as those in private practice. They were soon reporting that online costs, lack of computers, and lack of telecommunications were significant barriers to providing access to public health professionals.

Information infrastructure

At roughly the same time, the US government was taking significant steps to develop advanced computing and communications capabilities as a basis for establishing a national information infrastructure (NII). Some states had begun to implement high-speed statewide networks. NLM was the initial Public Health Service participant in the interagency High Performance Computing and Communications (HPCC) program [11], and NLM Director Donald A. B. Lindberg was appointed the first director of its National Coordination Office by the President's Office of Science and Technology Policy. By 1994, NLM was sponsoring a range of health-related applications of advanced computing and telecommunication technologies, including use of the Internet to support development of, and access to, an expanding array of NLM products and services (e.g., GenBank, the Visible Human, the Unified Medical Language System [UMLS] Knowledge Sources, NLM Websites), to support Internet connections for hospitals and health sciences libraries, and to support telemedicine projects and test-bed networks for sharing electronic patient data and images. Other federal agencies participating in the HPCC program also funded some health-related projects. With a very few notable exceptions (e.g., a study about automated tuberculosis detection [12]), none of the HPCC-funded projects focused on public health [5]. In fact, very few proposals for HPCC funding were submitted by the public health sector, reflecting lack of awareness and of information technology expertise.

In parallel with the development of the HPCC program, the Public Health Practice Program Office of the Centers for Disease Control and Prevention (CDC) was developing the concept of the Information Network for Public Health Officials (INPHO) [13] as a means for improving public health infrastructure, connecting elements of the fragmented public health system, and overcoming the isolation of many state and local public health professionals. A pilot INPHO program was initiated in the state of Georgia in 1992 with funding from the Robert W. Woodruff Foundation [14]. In 1993, the rapid deployment of a statewide emergency information system during severe flooding in Iowa provided a graphic illustration of the benefits of networking public health officials [15]. By the mid-1990s, CDC was
Table 1
Expansion of the National Library of Medicine’s public health programs and services: timeline of selected relevant events

| Date   | NLM activities                        | US information infrastructure, informatics | US health policy/standards |
|--------|--------------------------------------|---------------------------------------------|-----------------------------|
| 1989   | Outreach plan                        |                                             |                             |
| 1991   | Intramural HPCC projects              | HPCC legislation                            | HHS-wide data standards committee |
|        |                                      |                                             |                             |
| 1992   | NLM director appointed 1st director, HPCC coordination office |                                             |                             |
|        | Connections grants                   |                                             |                             |
| 1993   | HPCC research contracts               |                                             |                             |
| 1994   |                                        |                                             |                             |
| 1995   | “Making a Powerful Connection”        |                                             |                             |
|        | Term “public health informatics” appears in print |                                             |                             |
| 1996   | 1st PH informatics bibliography       | Telecommunications legislation               | HIPAA legislation           |
|        | PH explicit in grants announcements   |                                             |                             |
|        | Indiana HPCC project expanded to include PH |                                             |                             |
|        | Large scale vocabulary test           |                                             |                             |
| 1997   | PH Partners formed                    |                                             |                             |
|        | Free MEDLINE/PubMed                   |                                             |                             |
| 1998   | Initial NN/LM PH-focused outreach projects |                                             |                             |
|        | Initial PH Partners Website           |                                             |                             |
|        | MedlinePlus:services expressly for the public |                                             |                             |
| 1999   |                                        |                                             |                             |
| 2000   | NLM/AHRQ research training conference: informatics, HSR, PH |                                             |                             |
|        |                                        |                                             |                             |
| 2001   |                                        |                                             |                             |
|        | 2nd PH informatics bibliography       | AMIA Spring Congress: PH informatics agenda |                             |
| 2002   | RxNorm clinical drug vocabulary       |                                             |                             |
| 2003   | US-wide SNOMED license                |                                             |                             |
| 2004   | NLM designated lead in clinical terminology coordination |                                             |                             |
| 2005   | RWJF-funded public health tracks at 4 NLM-funded informatics training sites |                                             |                             |
| 2006   | Long Range Plan 2006–2016             |                                             |                             |

Each item is listed in the column for the most relevant category, with a ✓ in other columns if also applicable there. Acronyms: AHRQ = US Agency for Healthcare Research and Quality; AMIA = American Medical Informatics Association; CDC = US Centers for Disease Control and Prevention; HHS = US Department of Health and Human Services; HIPAA = Health Insurance Portability and Accountability Act; HPCC = High Performance Computing and Communications; INPHO = Information Network for Public Health Officials; NRC = National Research Council, National Academy of Sciences; PH = public health; PHS = US Public Health Service; RWJF = Robert Wood Johnson Foundation.

planning to fund INPHO projects in a number of other states.

Health data standards
In 1991, NLM joined Department of Health and Human Services (HHS) discussions about promoting standard electronic data interchange. The initial impetus was the desire of hospitals and insurers to reduce the administrative costs associated with health care [16]. Nonetheless, some agencies, including NLM, saw an opportunity to promote federal involvement in the development of clinical data standards, seen as a prerequisite for developing electronic patient records that would support better health care and allow automated aggregation of data for research and public health as a by-product of treating patients. The hypothesis was—and is—that the use of electronic data standards will enable more efficient and accurate transfer of data between health care and public health systems, thereby improving surveillance, detection,
and response to public health threats. Congress reached substantial agreement on legislative language to promote health data standards during the push to enact health care reform legislation early in the Clinton administration, but no health care reform bill was passed. That same language would reappear in slightly modified form in the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

In 1994, in the aftermath of the failure of health care reform, a newly established Public Health Service Health Data Policy Coordinating Committee, chaired by Roz D. Lasker, deputy assistant secretary for health (policy), again brought together representatives from all Public Health Services agencies to develop coordinated positions and strategies on a range of health data policy issues. NLM represented the National Institutes of Health (NIH) on the committee. Among the issues considered were the federal role in promoting and supporting health data standards, the need for greater participation by the public health sector in the development of administrative and clinical data standards, and the poor state of information technology infrastructure in state and local public health departments.

MAKING A POWERFUL CONNECTION

In 1994 Philip R. Lee, assistant secretary for health, and Roz Lasker contacted NLM’s director to explore what could be done to promote collaboration between the medical informatics and public health communities, to achieve more public health involvement in the developing NII, and to bring the public health perspective to expanding data standardization activities. Initial discussions led to a decision to hold a one-day conference followed by a one-day strategy session that would bring the public health and information infrastructure communities together to produce “a collective vision for harnessing the NII in support of the health of the public” [9]. NLM, the Office of the Assistant Secretary for Health, the CDC, and the Agency for Health Care Policy and Research (now the Agency for Healthcare Research and Quality [AHRQ]) cosponsored the conference, “Making a Powerful Connection: The Health of the Public and the National Information Infrastructure,” in NLM’s Lister Hill Center on April 19, 1995. In addition to people from state and local public health departments, public health associations, federal agencies (HPCC and public health), and private foundations, the invitees included librarians from each region in NN/LM and faculty from every NLM-funded medical informatics training program. Several of the librarians had significant experience in public health outreach. Attendees received a draft report that summarized key issues and opportunities prior to the meeting.

The conference was an endurance test for attendees, with a long agenda packed with presentations from public health officials, HPCC and informatics representatives, health policy experts, and health sciences librarians. The substance of the meeting and the lobby conversations were a revelation to many. For those engaged in medical informatics and high performance networking, it provided a picture of the range and magnitude of public health problems that might be amenable to help from advanced information systems and communications. For the public health professionals, it provided a compelling view of the potential public health benefits of advanced systems and introduced currently available services that could assist the public health workforce. For funders and information service providers, the meeting prompted greater interest in identifying public health needs and designing programs that might address them. April 19, 1995, was the day of the Oklahoma City bombing (announced during the meeting) and just a few weeks after the Tokyo subway sarin attack. The need for an effective public health response to manmade emergencies, as well as to natural disasters and emerging and persistent infectious diseases, was evident to everyone in attendance.

Twenty-five conference attendees representing all the key stakeholder groups stayed on to meet on April 20, 1995, to develop a strategic plan, based on the needs, priorities, and opportunities identified the previous day. The July 1995 report of the meeting and planning session outlined the following objectives:

- bring the broad public health community together to develop a comprehensive public health information strategy, including a compelling vision (and specific examples) of how NII technologies can improve population health;
- advance a nationally uniform framework for privacy, data standards, unique identifiers, and data sharing, without which it is very difficult to implement integrated health information systems;
- bring public health, health care, research, and informatics groups to the table to ensure that privacy of individually identifiable health information is protected in ways that permit critical analytic uses of health data and that standards for health data meet the needs of the diverse groups who collect and use health information;
- promote the use of information in public health through legislative initiatives (such as Performance Partnership Grants) that foster accountability for improving population health, overcome categorical barriers, and permit states to use federal funds to develop and maintain integrated health information systems;
- facilitate partnerships between the public health community and other sectors to identify and make progress toward common information goals (including both policy issues and health information systems projects);
- improve information technology skills among public health professionals through changes in curricula and new approaches to continuing education; and
- take advantage of all available opportunities to educate the public health and NII communities about the importance of the NII to population health and about information policy issues.

The report included thirty-nine recommendations arranged by stakeholder (i.e., state and local public health agencies, federal agencies, professional public health agencies, federal agencies, professional public health officials, HPCC and informatics representatives, health policy experts, and health sciences librarians). The substance of the meeting and the lobby conversations were a revelation to many. For those engaged in medical informatics and high performance networking, it provided a picture of the range and magnitude of public health problems that might be amenable to help from advanced information systems and communications. For the public health professionals, it provided a compelling view of the potential public health benefits of advanced systems and introduced currently available services that could assist the public health workforce. For funders and information service providers, the meeting prompted greater interest in identifying public health needs and designing programs that might address them. April 19, 1995, was the day of the Oklahoma City bombing (announced during the meeting) and just a few weeks after the Tokyo subway sarin attack. The need for an effective public health response to manmade emergencies, as well as to natural disasters and emerging and persistent infectious diseases, was evident to everyone in attendance.

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health associations, professional associations related to health care and informatics, and schools of public health). Because many desired actions required collaboration among these groups, the recommendations to the different stakeholders had considerable overlap. By a conservative count, twenty-five recommendations were relevant to NLM, in its various roles as federal agency, national information service provider, NN/LM coordinator, funder of advanced computing and communications projects, supporter of training and education programs, developer of the UMLS, and member of the Medical Library Association (MLA), the American Medical Informatics Association (AMIA), and other relevant professional organizations.

**PUBLIC HEALTH OUTREACH AND INFORMATION SERVICES**

One key recommendation led directly to the formation of the Partners in Information Access for the Public Health Workforce (Partners) and an array of new information services, training programs, and outreach projects aimed at public health workers, described elsewhere in this issue [17, 18]. Rapidly expanding access to the Internet, the elimination of charges for MEDLINE access in 1997, and the creation of MedlinePlus and other NLM services for consumers provided a propitious environment for the development of the Partners. In addition to fostering new services and programs, the Partners helped increase awareness of existing NLM AIDS and environmental health services. The Partners became a key vehicle for NLM, other federal agencies, NN/LM, MLA, and public health associations to use in implementing other recommendations from the 1995 meeting (e.g., to publicize relevant informatics training programs and funding opportunities to the public health community, to encourage and support information technology training for public health workers, and to use professional meetings to highlight the importance of the NII and electronic information services to the public health mission).

**PUBLIC HEALTH INFORMATICS**

Friede et al. coined the term “public health informatics” in an article by that name published in the 1995 *Annual Review of Public Health* [19]. At a time of increasing support for NII and increasing concern about emerging bioterrorism and other public health threats, the April 1995 meeting and the resulting report helped broaden interest in applying informatics research and development to the public health arena. Following the meeting, NLM took a number of concrete steps to respond to the report’s informatics recommendations. Friede was enlisted to assist NLM in preparing a comprehensive bibliography for the emerging field [20], covering the literature from 1980 to 1995. NLM revised relevant grant announcements (e.g., connections, research, training) and research contract solicitations to include explicit mention of public health as a focus area. In one notable case, the HPCC contract for the Indianapolis Patient Care Network was extended in 1996 at NLM’s instigation to add exchange of data between involved health care entities and public health departments [21]. This network became a national model for electronic disease surveillance and other types of regional health information exchange. NLM grants also funded seminal work on automated syndromic surveillance for early detection of bioterrorist acts and naturally occurring disease outbreaks [22]. Although a minor player in terms of dollars spent, NLM continues to conduct, support, and promote research and development that illustrate the benefits of applying advanced informatics to public health and disaster management. Relevant recent projects include computational tools for the DNA identification of World Trade Center attack (and later Hurricane Katrina) victims [23], wireless access to hazardous substance information for first responders [24], advanced networks for coordinating medical responses to large-scale disasters [25], use of flu genome data to gain new insights into the evolution of flu viruses [26], and analysis of large data sets to determine the possible impact of curtailed airline traffic on flu transmission [27].

In the aftermath of the 1995 meeting, NLM staff members were instrumental in promoting inclusion of public health systems, issues, and experts in AMIA meetings. The 1996 AMIA spring congress, “Conquering Distance: Teleinformatics, Telemedicine, Telehealth” [28], chaired by an NLM employee, was the first to include public health as a major theme and a state public health director as a plenary speaker. This meeting also featured a one-day session jointly sponsored by MLA’s Medical Informatics Section. Five years later, the 2001 AMIA spring congress was wholly devoted to developing a national agenda for public health informatics [29]. A meeting originated from an NLM suggestion, NLM staff members helped organize the standards track and updated the public health informatics bibliography [30] in conjunction with the meeting. As noted in the introduction to the 2001 bibliography, there had been a marked increase in publications on the topic since the first bibliography was published in 1996.

Obviously, one way to increase public health informatics research is to increase the number of people with the advanced training required to conduct it. After NLM signaled its interest in the mid-1990s, the number of faculty and students in NLM-funded informatics training centers working on public health issues gradually increased. To promote the development of curricula and institutional arrangements that would encourage work at the intersection of medical informatics, health services research, and public health, NLM and AHRQ cosponsored an invitational conference in 2000 [31] to discuss ways to promote greater synergy between NLM-funded informatics research training programs and AHRQ-funded health services research training programs, some of which were located in the same universities. The results of this effort were modest. NLM also talked to CDC about funding additional public health informatics slots in NLM’s existing informatics training programs, but CDC pre-
ferred to focus on an internal informatics training program. In 2005, this idea came to fruition in a different form through an innovative collaboration between the Robert Wood Johnson Foundation (RWJ), the Foundation for NIH, and NLM. Under this arrangement, NLM administers a grant from RWJ, which funds special public health informatics tracks and additional fellows at four of the eighteen NLM-funded informatics training sites for at least four years. Special meetings and activities for the RWJ-funded fellows are open to any NLM-funded informatics fellow focused on public health, regardless of their training site. Some joint activities with CDC’s informatics training program have been initiated.

HEALTH INFORMATION POLICY AND STANDARDS

Immediately following the 1995 meeting, NLM promoted the inclusion of public health representatives and issues in high profile health information policy studies. An important example was the National Research Council (NRC) study on maintaining privacy and security in health applications of the NII initiated by the library in late 1995 and published in 1997 as For the Record: Protecting Electronic Health Information [32]. For the Record provided a blueprint for subsequent federal health data security regulations. In requesting the study, NLM identified state public health departments as a key group to be represented on the study committee and required the inclusion of a system run by a public health department in the site visits that were integral to the work. The library also highlighted public health concerns in commissioning the NRC study that resulted in the publication of Networking Health: Prescriptions for the Internet [33] in 2000, which emphasized the importance of federal leadership in establishing a national health information infrastructure.

The report of the 1995 meeting recommended that public health views and needs be incorporated in ongoing efforts to develop standards for electronic health data. It specifically charged NLM to include concepts and terms important to public health in the UMLS. A serious attempt was made to engage public health participation in a 1996 large scale test to evaluate the coverage of existing controlled vocabularies in the UMLS [34], but it was largely unsuccessful, due to the lack of public health systems with locally developed vocabularies that could be used in testing.

In addition to prompting significant progress toward health data standardization in the United States, HIPAA was an important stimulus for increased public health participation in health data standards activities. HIPAA’s provisions for administrative simplification mandated the adoption of standards for electronic interchange of administrative transactions and a study of the appropriate role for the federal government in standards for patient record information. As outlined in the 1995 report, many existing health data standards had been developed with little input from the public health sector, due to the time and money required for serious participation in standards development. There was concern that a lack of public health involvement in the HIPAA standards process and in the development of patient data standards could have long-term negative effects on the efficient interchange of data between the health care system and public health authorities. The National Committee on Vital and Health Statistics, which was responsible for overseeing the implementation of HIPAA administrative simplification, encouraged the Department of Health and Human Services to provide a vehicle for meaningful public health participation in standards activities. In 1999, CDC’s National Center for Health Statistics established the Public Health Data Standards Consortium [35], with AHRQ’s support, to increase public health participation in the development of health data standards, NLM was a charter member. A side benefit of the 2001 AMIA spring congress was that it publicized the existence of the consortium to many public health professionals who were unaware of it.

The extent to which public health may need its own standard vocabulary—as opposed to its own view or organization of concepts and terms also important in health care, preventive medicine, environmental management, etc.—is a topic of continuing discussion, but there is no disagreement that public health considerations should be reflected in the development, maintenance, adoption, and dissemination of standard clinical vocabularies. The fact that US public health surveillance relies on data from state public health authorities, which in turn depend on data from many local public and private organizations, has influenced national policy regarding federal funding of standard clinical vocabularies to enable free use and therefore promote adoption by all appropriate parties [36]. NLM has played a significant role in developing this policy and has major responsibility for its implementation. The library currently funds, licenses for US-wide use, or builds three major clinical vocabulary standards (LOINC, SNOMED CT, and RxNorm) and disseminates these and other standard vocabularies free of charge in the UMLS Metathesaurus [37]. The CDC has provided important input on public health requirements during the negotiations that resulted in the US-wide license for SNOMED CT. The CDC continues to provide significant input to the ongoing development of both SNOMED CT and LOINC [38].

THE NEXT DECADE

In the last ten years, NLM took advantage of a propitious environment to increase the visibility and understanding of US public health information challenges and opportunities. The library helped build a range of partnerships that produced new information services, increased public health informatics research and training, and promoted health data policies to benefit the public health workforce and the diverse populations it serves. Events at the opening of the twenty-first century highlighted the importance of a strong public health system capable of responding to terrorist attacks (9/11, anthrax, Madrid, London, Bali, Egypt), managing the aftermath of natural disasters (tsuna-
mis, earthquakes, hurricanes), detecting and minimizing disease outbreaks (West Nile virus, SARS, bird flu), and preventing conditions caused by risky or unhealthy lifestyles (accidents, AIDS, obesity). These events also provided a stark reminder that, in an important sense, all disasters, emergencies, and health problems are local. Effective response depends on rapid and accurate communication of information within, from, and to the affected localities. Such communication depends on both social and technical networks—in other words, community partnerships, supported by effective statewide, regional, and national arrangements. The benefits of this approach were evident in the NLM, NN/LM, and library association support of the efforts of health sciences and public libraries in responding to the effects of Hurricane Katrina [39, 40]. Similar cooperation and communication also underpins the MedlinePlus GoLocal initiative, which connects information about local health services to authoritative national descriptions of health conditions and treatments [41].

In the next decade, NLM, health sciences libraries, public libraries, and public health agencies will continue to be natural allies in addressing two major problems of our age: the need to improve health literacy [42], which is a prerequisite for informed choices about health, and the development of robust procedures for managing the health effects of disasters. In many instances, the latter may depend on the former. The NLM Long Range Plan for 2006 to 2016 [43] emphasizes expansion of these alliances to improve health literacy and disaster information management, continuing support for public health informatics research and standards development, and a stronger focus on disaster information management research.

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