Improving Health Care through Information: Research Challenges for Health Sciences Librarians

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ABSTRACT

RESEARCH QUESTIONS IN HEALTH SCIENCES LIBRARIES are influenced by the health care environment. Three fundamental problems underlie most research in health sciences librarianship: determining what therapies are effective and of good quality, delivering information when and where it is needed, and in forms that will increase its use. Adapting to sweeping changes in all kinds of libraries is made more complex because of equally challenging shifts in medical practice and consumer health. Developments in health information research will be advanced through collaboration across disciplines and between organizations.

INTRODUCTION

While many of the problems and issues facing health sciences libraries are held in common with other libraries, problems and issues specific to health sciences libraries are driven by the agenda of the health sciences in general. In health sciences, as perhaps in no other major library sector, the strength and importance of the national library, of grant funding, and of the community of users themselves, drive the direction of research. While health sciences libraries certainly face issues of collection preservation and management, digital library system design, effective organization and staffing, and public relations, health sciences libraries have unique challenges and opportunities. Health sciences libraries operate within the environment of health care delivery and are therefore affected by the trends and factors that characterize this environment. Quality health care—accessible to all who need it, at a fair price—is the primary driver in the health care

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environment. Fundamental to virtually every issue in health sciences librarianship is one or more of the following problems:

- Determining what therapies are effective and of good quality;
- Delivering information when and where it is needed in forms that will increase use;
- Developing an effective economic model.

This situation is not new. The Medical Library Association (MLA) founded the Library Research Section in June 1982; one of its stated purposes was to serve as an action group for the advancement of library-related research. This purpose was later expanded in 1996 when the name was changed to the "Research Section" to reflect interest in general research, not just that of libraries.[1] In the 1990s, MLA undertook the development of a policy statement on research. The opening paragraph of the research policy reflects these central concerns:

> Society is concerned about access to high-quality health care at reasonable cost. Increasing numbers of health care leaders recognize the importance of information to excellent, affordable health care. Clinical decisions should be based on the scientific evidence traditionally recorded in the health sciences literature. The development and use of evidence-based practice guidelines demand a sophisticated analysis of the literature, creative ways of delivering information to practitioners at the point of care, and an understanding of the effect of information on practice patterns and costs. There is a growing need for computer-based patient record systems that can generate new scientific knowledge as a by-product of current care. (Medical Library Association, 1995, p. 4)

This statement reflects the influence of three external events that have resulted in sweeping changes affecting the role of health sciences libraries. As with all libraries, the advent of the Internet irreversibly altered practice, but in health libraries especially, the availability of free, public access to MEDLINE signaled a major shift in emphasis by the National Library of Medicine (NLM) toward providing health information to the public. Second, the report issued by the American Association of Medical Colleges (AAMC), which introduced the concept of the Integrated Academic Information Management System (IAIMS) in 1982, has continued to alter the landscape of academic health information centers, just as the release of the 1994 Joint Commission's *Standards for Accreditation of Health Care Organizations* affected hospital libraries.[2] Third, the rise of the evidence-based medicine movement has affected the role of information (data and knowledge) in the practice of medicine.

Within the practice of librarianship, the changes have been no less dramatic. Libraries as organizations have traditionally been concerned with the acquisition, organization, and dissemination aspects of the information transfer cycle. With the advent of digital information where "everyone is a

publisher," librarians have increasingly become concerned with the creation of information. And, as they become collaborators in the design of information systems, they increasingly become involved with the *use* of information. These changes are especially apparent in the health sector, where health sciences librarians are beginning to recognize that "collections of data aggregated from individual health records, like the clinical data warehouse or the population health data set, can be viewed as part of the larger digital library needed to support biomedical research, education, and informed health care decisions" (Humphreys, 2000, p. 446).

In addition to, or perhaps because of, the magnitude of the changes and the importance of medicine, the field of biomedical information now includes a variety of potential collaborators, all of whom claim legitimate interest in the digital health library. As Betsy Humphreys (2000), associate director of the National Library of Medicine states, viewing health data as part of the digital library "not only opens up new funding opportunities but may also encourage fruitful multidisciplinary cooperation on problems common to knowledge based information and aggregated health data, including permanent retention of electronic information or the need to implement variable user access privileges" (p. 446).

The breadth and complexity of the research problems that this statement raises extend beyond the ability of a single researcher, or even a single sector of the health care environment. Collaboration across sectors is necessary, and substantial funding is essential. As health sciences librarians position themselves as players within this larger environment, they open opportunities for participation in and support from, the National Institutes of Health (NIH) through the NLM. At the same time, librarians must either compete or collaborate to ensure that they remain players in this domain and that the values associated with librarianship continue to be acknowledged in the development of research agendas.

This represents a major change from the early origins of the field. For most of the past century, academic medical libraries functioned much as academic libraries everywhere, working with faculty and students to support the medical school curriculum. In the clinical arena, hospital libraries served the information needs of physicians and, more recently, those of nurses, administrators, and allied health personnel. Increasingly, librarians compete with medical informaticians, basic scientists, health service statisticians, and clinicians for ownership of problems and approaches. A benefit to this competition is that the problems and research in this area are understood and shared to some extent by others and that a broader array of resources, both financial and methodological, can be brought to bear on problems. The multidisciplinary approach also can determine which research questions will be pursued.

Health sciences libraries form an integral part of the fabric of medical informatics, and librarians form an integral part of the research team. Thus,

the research problems that characterize this field are not limited to librar-
ies *per se,* but are driven by the role of libraries and librarians in resolving
issues that extend beyond formal library organizations and that certainly
include, and even center on, problems of digital libraries and knowledge-
based information and documents. Librarians have traditionally been con-
cerned with knowledge-based information, and this will certainly contin-
ue to be the case in the future. However, problems of knowledge-based data
can no longer exist in isolation from clinical data in order to resolve the
problems facing health information systems in society. Because knowledge-
based information is one component of "health information," librarians
must work together with other health professionals to solve these research
problems. The remainder of this article will focus on how these three fun-
damental factors—quality, delivery, and economics—form the central fo-
cus of research in health sciences librarianship. It will conclude by placing
these health-related issues against the backdrop shared by all types of librar-
ies, such as the evolution of digital libraries and the tension between en-
suring universal access to information while protecting individual privacy
and intellectual property.

I. QUALITY: DETERMINING WHAT THERAPIES ARE EFFECTIVE AND OF GOOD QUALITY

Delivering quality health care to patients is central to the practice of
medicine. To determine which therapies are most effective, to select which
procedures "do no harm," and to manage one's practice in a cost-effective
manner requires lifelong learning and continual updating. Yet, the vast size
and rapid growth of the biomedical literature is an acknowledged imped-
iment to maintaining currency in the field. According to some estimates, 2
million articles on medical issues are published annually worldwide (Balas
& Boren, 2000, p. 65). To read everything of potential biomedical impor-
tance, it has been estimated that physicians would have to peruse 6,000
articles per day, and a general physician who just wants to keep up with the
literature relevant to her practice would face the task of examining nine-
teen articles a day every single day of the year! (Balas & Boren, p. 66). In
their role as providers of knowledge-based information to clinicians, med-
ical librarians have traditionally culled the most relevant and precise infor-
mation in response to a query. With the growth of end-user access to data-
bases, medical librarians support clinicians and other health personnel in
developing information management skills so that they can retrieve appro-
priate information to meet their information needs independently. In the
last twenty years, however, medical librarians have extended these roles to
include selecting the *best information* to fill the need. This practice—select-
ing the best articles, not simply those that are most relevant—is called qual-
ity filtering. It was first developed at McMaster University; McKibbon (1998)
and others have written extensively on the concept and have been the pri-

mary developers of various techniques to ensure quality retrieval. Some librarians have taken quality filtering to its next logical step—participation in evidence-based medicine initiatives.

Evidence-based medicine, or more broadly referred to as evidence-based practice, is defined as the management of individual patients through individual clinical expertise integrated with the conscientious and judicious use of current best evidence from clinical research (Sackett, 1996). Originating in Great Britain with the Cochrane Collection, evidence-based medicine seeks to analyze research and to identify those studies that meet stringent guidelines of quality. The findings in these studies constitute the evidence upon which clinical guidelines for practice are based. The process requires extensive searches of the biomedical literature to identify the body of relevant studies. A team of experts, sometimes including librarians, examines the studies to determine whether they meet stringent criteria set up for scientifically valid research. The findings that meet this "gold standard" are then further analyzed and the results compiled into guidelines for clinical practice. Thus, the "evidence" referred to in "evidence-based medicine" is the scientific evidence that underlies current standards of practice. Evidence-based practice (EBP), then, is practice based on evidence that is found to be empirically sound and verifiable; it may be modified where necessary by the clinical judgment of the practitioner, based on his or her observation and experience. The role of librarians in this enterprise has been studied and advocated by Scherrer and Dorsch (1999), among others.

This shift, from relevance to utility/effectiveness, requires that librarians be capable of conducting additional analysis of the literature. For many years, the indexers at the NLM have tagged articles to indicate the type of research reported. The number of these tags is continually expanded so that articles that meet the standards of a randomized clinical trial (RCT), for example, are identified and searches can be limited to only those studies that meet the RCT "gold standard." Since the body of literature retrieved may be larger than an individual has time to read and absorb and little work has been done to determine to what extent these limits are actually invoked, we know little about the actual effectiveness of this indexing enhancement.

While librarians are familiar with the traditional indicators of quality in the literature, such as peer review and citation patterns, identifying and selecting literature that is of greatest utility or effectiveness requires an additional set of criteria. Cranfield's early studies on precision and recall were among the first in a body of research literature that focuses on information retrieval (IR). The IR research stream provides a basis for understanding the effectiveness of indexing filters, but additional research is needed to fully understand how to design systems for effective and efficient quality filtering that can be applied to evidence-based practice. The results of information-retrieval studies should be diffused to those who develop information delivery systems in order to ensure that any technological so-

lutions designed to meet clinical information needs effectively locate the appropriate literature.

In addition to examining the process of retrieving information, the literature itself presents an important research area. According to the report of a recent symposium sponsored by the American Medical Informatics Association (AMIA), medical literature is still beset with problems of research design; furthermore, even literature of high quality remains inaccessible to the practitioner (Sim et al., 2001). What is the role of librarians monitoring and encouraging quality medical literature, particularly information aimed at and available to consumers? The work of Ann Weller on the process of editorial peer review and its effect on quality should be continued to advance understanding of the way medical knowledge is created, controlled, and disseminated (Weller, 1987, 1990, 2002). Editors, publishers, peer reviewers, database developers and distributors, and indexers all work to ensure that quality literature is published, indexed, disseminated, and retrieved. How should their performance be evaluated? How might electronic publishing affect these practices? How can the "best" literature be assured of dissemination? How can mediocre and even erroneous literature be identified as such? And, how can these "controls or filters" be implemented without threatening the free flow of information?

Librarians continue to demonstrate their key role in the information transfer cycle by advocating that information be made available at a fair price. Librarians at the NLM also are responsible for the quality of the indexing, the selection of the journals to be indexed, the monitoring and testing of the interfaces and search engines that retrieve the literature, and even for the peer review of the literature. They also participate in the teams that select the articles for clinical guidelines, and identify the gold-standard RCT literature. Finally, they can be participants in the teams that identify and evaluate the literature that is brought to bear in the embedded, knowledge-based systems. Improved health care demands that practitioners keep up with the latest techniques and have the ability to evaluate the literature so as to know when to incorporate findings into practice.

It is almost a truism that the format and standards for research publications have remained stable for decades, despite the reality that most clinicians find research hard to read and understand, and even more difficult to apply the findings to practice (Balas & Boren, 2000). There is a body of literature on improving the clarity of abstracts, as well as their readability, but much of this research has been conducted outside of library and information science (Hartley, 2000) and focused primarily on the print literature. The effects of structured abstracts and other access mechanisms on the use of the literature and its effect on actual clinical practice, particularly as more and more literature is available electronically, has not been fully investigated. Standards for structured abstracts and their relationship to the indexing that is applied to them and the search engines that retrieve

them are all important research areas in which librarians have both the interest and expertise to make valuable contributions.

II. DELIVERING INFORMATION WHEN AND WHERE NEEDED IN FORMS THAT INCREASE USE

Quality control of the literature is essential and the next step is ensuring that those in practice heed the findings of that literature. In short, it is the problem of connecting knowledge with practice. It has been recognized for decades that the diffusion of innovation is a remarkably slow and inefficient process; in medicine, it takes an average of seventeen years to implement clinical research results in daily practice (Balas & Boren, 2000, p. 66). Underlying the concern for timely delivery of valuable clinical knowledge is the prevention of health care errors. The Institute of Medicine's (1999) recent study revealing the extent to which medical errors are costing human lives and precious dollars has spurred greater interest in developing approaches to reduce errors a well as to improve clinical practice. Reducing error includes both errors of omission and commission, inappropriate therapy selection, and incorrect or incomplete diagnoses, as well as "mistakes" such as wrong dosages, flawed technique, or failure to prevent infection or contamination.

Connecting information with people has been a long-standing role for librarians and the ways in which this connection takes place are changing and expanding. The health sciences literature in the last several decades reveals a number of initiatives to increase the involvement of librarians in delivering information to the bedside. Determining the most efficient and effective ways of facilitating the diffusion of innovation to clinicians is an important and needed area for further research. Reports of programs such as clinical librarianship and the recent call for a new health professional, the informationist, have been largely anecdotal and hortatory (Lipscomb, 2000; Davidoff & Florance, 2000). The MLA and the NLM cosponsored a conference on the informationist concept in April 2002; a number of questions were raised about appropriate training, viable economic models, and the impact of the informationist on clinical outcomes (Shipman et al., 2002).[3] For example, systematic evaluation of clinical librarianship programs in a variety of settings, or a head-to-head comparison of multiple techniques would help determine which of these should be more actively pursued. Identifying variables and multivariate techniques to investigate how adoption of innovation takes place, and how this adoption can be encouraged are just two of many possible areas needing investigation.

Observation of information-gathering behaviors also contributes to developing delivery systems that actually work. Understanding the information behaviors of clinicians—how they seek information and how they apply it to practice—is a crucial first step in designing information delivery systems. In her 1998 review, Detlefsen concludes that the studies that have

been conducted have done little to build a theoretical framework from which to generate and test hypotheses. Furthermore, the environment in which most of these studies were conducted has changed dramatically. Detlefsen notes the potential effect of managed care; even more important is the growth of digital information. Often, these studies conclude that the clinicians do not have access to appropriate information (or they perceive that they don't) or that they do not understand how to use the information system and its results appropriately, or both. The enormous variety of specialties, the disparity among practice environments, and the number of varying information access points make it challenging to draw generalized conclusions.

Examining how information is used in order to design delivery systems is a high-stakes enterprise from which librarians can benefit in their efforts to find better ways of helping clinicians manage information in the course of their work (Ash et al., 2001). Librarians have an especially important contribution to make to this research. Because they have traditionally been personally and immediately engaged in assisting clinicians with information seeking, they are uniquely positioned to gather data by observation or survey, for example, that will augment the existing literature on information seeking and use. Librarians have already acquired considerable understanding in this area, as evidenced by the recurring chapters on information needs and uses in the *Annual Review of Information Science and Technology*. Extending this research stream further into health sciences is the next obvious and important step. Furthermore, the insights gained from this research are valuable to systems developers and producers both in the nonprofit and profit sectors, who are most interested in creating products and services for this market.

Knowledge management (KM) also offers an opportunity for applied research in health sciences. First developed in the business sector, knowledge management was adopted by corporate librarians as they have attempted to use its techniques to optimize those assets of an organization that reside in the heads of its employees—its knowledge workers. Knowledge managers elicit expertise, organize it, and make it available throughout an organization in order to deliver value to a business (Broadbent, 1998, p. 24). In a health care environment, knowledge managers can use and exploit the clinical expertise that resides in the organization and its professional staff to advance the mission of the organization. Knowledge management can also invoke "stored knowledge" that resides in external databases and knowledge sources in order to support and guide clinical decisions. While these appear to be fundamentally human activities, many KM applications are highly dependent on information technology. A recent example that should attract the attention of LIS researchers is a physician order entry system with built-in checks, balances, and alerts to create a "seamless web" in which the clinician no longer has to engage in information seek-

ing at all, but is "fed" information at a given point. Davenport and Glaser (2002) characterize one such clinical decision support system (CDSS) as having knowledge or information "baked in" because no separate information system need be pursued. Given the financial rewards available in the health care field, comparing a KM system that has an information intervention that is automatic and seamless against more traditional interventions mediated by information professionals raises questions that are urgent in their implications for the future of professional judgment.

Since it seems inevitable that CDSS will be an important tool for reducing medical errors, the design and development of CDSS can draw upon insights contributed by LIS research. LIS experience with point-of-use instruction embedded in catalogs and databases could be useful in designing CDSS and ensuring their use. Determining how the knowledge from the literature might best be "baked in" begs to be investigated. How can the findings of science be presented in ways so that they are accessible and useable by those charged with applying them? How can both literature-based and practice-based research evidence best be translated into machine-interpretable formats suitable to clinical decision support systems? In order for CDSSs to be built, there must be mechanisms to link the knowledge-based data to the system, to invoke it appropriately, and to update it consistently in a timely fashion. Can some formats that already exist—such as structured abstracts and enhanced indexing—be adapted for testing? And, can the results be disseminated to system developers and to opinion leaders within the health professions?

The kind of mandatory alerting and knowledge management that may be required for health care professionals differs from the delivery mechanisms traditionally offered to patients and consumers. While patients can be exhorted to become more knowledgeable and thus more responsible for complying with the course of therapy prescribed by their physicians, no such mandate currently exists for the well public. Because many, if not most, public library transactions take place by choice, examining information seeking behaviors and choices is a crucial research question. Consumers retain the freedom to choose whether to seek information and where and whether they will use it. The public library is a primary channel for this communication to take place, and designing systems for consumer health information dissemination is an important research topic. Describing the ways in which the general public can obtain high quality information and determining its effect on the health of the general population affects how libraries and librarians collaborate with the health care establishment. Some important lines of communication have already been established between the NLM, the MLA, and the American Library Association (ALA), in particular the Public Library Association division of ALA.

How to deliver information when and where it is needed in a form that will facilitate and encourage its use is an age-old question in library and

information science research, but the environment in which delivery of health information occurs continues to change. In the clinical arena, when patient care is at risk, information use by directive is becoming more acceptable. In such a scenario, information use cannot be avoided, and people become information users by force. In order for this to be acceptable to professionals, the information presented must be of the highest quality and relevance, or they will resist using the system that presents it. And indeed, some have expressed concern that automation has not always been beneficial and may negatively affect the ability of an organization to function effectively. Designing digital repositories of evidence drawn from multiple sources (literature, patient data, numeric values and statistics, for example) that can be shared among various audiences was recently named as a key area of research by medical informaticists; clearly it is a key area for librarians as well (Sim, 2001). In addition, testing the efficacy and cost-efficiency of decision support systems that involve a skilled human intervention versus those that are purely automatic has implications not only for physicians, but across many sectors in health care, particularly in nursing and in allied health, two areas that are frequently overlooked.

Library research has often focused on instructional effectiveness in helping users to navigate information systems. While there is certainly an argument to be made for including information literacy in medical school curricula and for providing updates to practicing clinicians, instruction is generally not viewed as an appropriate solution for clinicians. The real issue in demonstrating effective use of information in clinical care is reduced error and behavioral change. In this environment, instruction is important only insofar as education can be said to drive behavioral change. Questions that need to be asked include: "How can the rate of dissemination of information be increased so that behavioral change is effected?" "Does the human intervention of information professionals increase that behavioral change?" "Even if it does, is it affordable? Or, is the development of clinical decision support systems (CDSS) a more effective way to go?" "If the latter, how can the findings of research literature be made available in an efficient way so that they are incorporated into the CDSS in ways such that the integrity of the literature that librarians have come to know and value is preserved?"

III. ECONOMICS: DEVELOPING AN EFFECTIVE PRICING STRUCTURE

Providing knowledge-based information—in whatever form and through whatever channel—has costs attached to it. If costs can be examined so that we understand the value of them, a price can be put on them. In the world of health care, discussions of price are inevitably driven by the question, "Who pays?" The answer to this question should lie in questions of value—To whom is the information valuable? Or in other words, what

difference does it make? If it can be demonstrated that availability of information makes a difference in outcome, in length of stay, in efficiency, in quality of care, then a third party such as an insurer is far more likely to cover the cost. If not, the cost is yet another "add-on" to an already enormous health care price tag. Despite the belief that something that affects a human life has value beyond the economic, the fact remains that belief systems that cannot also demonstrate economic value are far less likely to be implemented. Any discussion of economics, then, must originate with an examination of impact—what difference does it make?

The health science literature, and indeed the LIS literature in general, is sprinkled with studies that have attempted to address the impact question (Klein, et al., 1994; King, 1987; Marshall, 1992; Lindberg et al., 1993) These studies, though valuable, are limited in scope and generalization. Indeed, Urquhart and Hepworth (1996) compared several studies of the value of information to clinical decision-making and concluded that care must be taken when replicating a study in a different health context and culture and that multiple measures as well as openness to multiple outcomes are essential. Most studies are limited in that they also assume the intervention of an information professional; that is, they query clinicians as to whether an information intervention was helpful or not. A more useful question with less potential for bias is, "Does availability of information [in any form delivered through any channel] affect patient health care?" And even more interesting, "*How* does it affect patient care?" These questions, particularly if they are asked objectively without the possible bias of attempting to support the role of a particular kind of information intervention, are essential.

The MLA recently initiated a multiphase study aimed at determining the contributions of library and information services in health care. A preliminary taxonomy has been published that will serve as a basis for further research by generating hypotheses aimed at deriving the best approach for information centers to use in assessing their value (Abels et al., 2002). The underlying questions in the study are:

- What is the value of using library and information services to the hospital or academic health sciences center?
- What are the contributions that librarians, through the provision of services, make to the bottom line of the organization?

The taxonomy has five broad concepts that reflect the mission of hospitals and academic health sciences centers: clinical care, management of operations, education, research and innovation, and service. It builds upon and extends earlier work by Saracevic and Kantor (1997) who developed a taxonomy to assess the value of LIS to another specific population group—researchers. Saracevic and Kantor, however, concentrate on demonstrating the value of information to the *individual user,* while current and future research in health science must focus on the value of the information to

the *mission of the institution*—improved patient care (Abels, 2002, p. 279). Since reducing medical error results in both more effective health care, but also more efficient health care, it is of demonstrated value to an organization. Effective error reduction is a measurable result both in economic terms and in terms of quality patient care.

Bringing together organizations and institutions whose missions may be similar but whose practices, value systems, and cultures are different remains an enormous challenge, one whose resolution may lie beyond the ability of traditional research. Nevertheless, systematic observation and reflection, as well as political and economic models, may guide future activities. Determining what incentives are attractive to foster interorganizational cooperation is one area that might be investigated. Are there non-economic incentives, for example, that will encourage the construction and adoption of standards across health care sectors? Another big challenge for development of informational systems is electronic publishing; questions of licensing, copyright, and fair use abound throughout the entire information transfer cycle. It is notable that the NIH and the NLM have taken positions on these issues. Some derive from what might be termed their "legacy"—their products are already "owned" by the U.S. government—and their choice—PubMed makes full text of selected journals available over the Internet through the MEDLARS systems. Because the NLM is both creator and publisher of some key information products and services, it has adopted the strategy "to use its own products and services as test-beds for technical and organizational approaches to organizing and managing digital information. The Library's goal is to gain experiences from concrete experiments so that it can contribute to the development of workable national standards and strategies and also provide useful advice to other publishers of electronic information" (Humphreys, 2000, p. 450). Despite these important and laudable moves, many questions remain. What are appropriate business models for electronic publishing, especially in areas where information is needed to advance health care? How do libraries, publishers, and scientific societies develop business models that address the key challenges facing the production, dissemination, and preservation of scientific information?

The design and implementation of effective delivery mechanisms—whether computer-based or human-based—is directly tied to the economics of health care, and the economy of health care information differs from other similar sectors in important ways. First, the major indexing system is in the public domain. The MEDLINE system and all its components are produced by the NIH, a federal agency, and therefore it costs much less to use MEDLINE than other databases in the sciences. Furthermore, it is available for research purposes at a reasonable cost. Second, the grants program of the NLM makes research into health informatics attractive and accessible to qualified researchers, particularly multidisciplinary teams. With these

resources available, there are opportunities to build a solid research base and armamentarium of tools that can be used both at the individual evaluation level but also at the level of large-scale research studies. Greater sophistication in articulating theory and identifying variables, as well as triangulation between qualitative and quantitative data, would advance understanding considerably. There is a continued need to assess the value of information services to the improvement of patient care. To the extent that library and information interventions can be shown to make a contribution to achieving any of the organization's mission-related goals, they contribute to the bottom line, even if the specific benefit of the contribution cannot be isolated or measured in monetary terms.

IV. DIGITAL LIBRARIES, INFORMATION ACCESS, AND INDIVIDUAL PRIVACY

Research focusing on the role of information in health care ("informatics research") is conducted today in a changing political, economic, and social environment. In an informatics research agenda, the AMIA named several factors affecting health care informatics: the growing availability of health information, changing roles of health care consumers and providers, globalization, more fluid institutional boundaries, increased politicization of health care, and changing work standards and practices. These factors interact with the increased ability to create more integrated information systems capable of linking clinical, personal, and organizational performance data with the drive to develop computer based lifelong patient records and establish systems that are interoperable, even across international borders (Kaplan et al., 2001). Although this agenda originated from an AMIA meeting, health sciences libraries and librarians are part of this environmental evolution, as indicated earlier, because of their involvement in organizational changes brought about by the IAIMS report, Joint Commission on Accreditation of Healthcare Organizations (JCAHO) standards, and digital libraries.

The term "digital libraries" has become an accepted part of modern vocabularies, yet it often takes on varied meanings. In health care, digital libraries may include health record data as part of the library, leading them to be described as a "Web-era reformulation of the long-standing informatics goal of seamless integration of automated clinical data and relevant knowledge-based information to support informed decisions" (Humphreys, 2000, p. 444). When the scientific literature is seen as a collection of print-on-paper articles, and the patient medical record is a chart of handwritten notes, transcriptions and coding for financial reimbursement, the two appear to have little relationship to one another. But when they are converted to a digital format, each can be viewed as simply another node in the information transfer cycle. Furthermore, when the coding systems used to analyze and retrieve items are rationalized so that they interconnect, sud-

denly a web of patient data and knowledge-based literature emerges. The vision, funding, and architecture to create a method for these varied systems to interconnect originated with the NLM's Unified Medical Language System (UMLS) project in the mid-1980s. The UMLS maps relationships among various coding systems used in the medical environment such as the International Code for Diseases (ICD), Clinical Procedural Terminology (CPT), and Medical Subject Headings (MeSH). Constructing the UMLS has been an enormous and complex undertaking, one that probably could not have been accomplished without the resources of a major institution such as the NLM for which it was a priority. As the idea and the reality of IAIMS evolved, the value of a system capable of linking and integrating different types of digital biomedical information became increasingly recognized. Furthermore, it provides a workable example of a digital library, presenting the user with a coherent view of an organized, selected, and managed body of information.

When this goal was first formulated it was assumed that clinicians were the targeted beneficiaries of the program. As the audience for health information has expanded to include public health professionals, patients, and the well public (consumers), there is a need to make information available to support patients' participation in choosing treatments and deciding on strategies for managing their health problems.

Along with its obvious benefits, the availability and delivery of health information (knowledge-based literature, clinical guidelines, and health record data) has introduced many complex policy questions. Solutions to these questions will require investment in the production of better materials, training for clinicians and other information providers in how to use them, and the development of an accreditation system to help users to judge the quality of health information. Now that various systems can "talk" to each and data can be shared rapidly and easily across geographic, conceptual, and administrative barriers, what controls must be put in place to assure access while protecting privacy? Indeed, at the 2001 spring conference of AMIA, a series of recommendations for public health informatics recognized that a major challenge is to develop "coherent, integrated national public health information systems that will integrate efforts between public health and clinical care systems and will address pervasive concerns about the effects of information technology on confidentiality and privacy" (Yasnoff et al., 2001, p. 536). It can be easily seen that the research questions that emerge from the creation of the "seamless web" extend beyond technology application and evaluation into policy analysis. Some of the policy research may be guided by the increasing involvement of the library community in the design and delivery of consumer health information.

SUMMARY

Research in the health sciences is characterized today by a need for multidisciplinary approaches—not just in methodology but through real collaboration. Health care is a major factor in national economies, and it affects everyone. Those for whom information is a central concern are challenged to describe how information makes a difference in health. Making sure that clinicians are provided with the best information that truly describes effective therapies, ensuring that consumers and patients have access to reliable information, and determining how best to deliver that information in a form that will be used are enormous tasks. While research alone cannot change the world, it can provide insight and direction to those who are in a position to take steps that will make a difference. Health sciences librarians and those who are concerned about the future of health sciences libraries are in a position to bring their expertise, their values, and their commitment to ensuring that the information infrastructure that supports health care decisions is the best it can be and that it is available to all who choose to use it.

NOTES

1. The history of the Research section, written by Robert Braude, is available at http://research.mlanet.org/. Accessed November 7, 2002.
2. For a discussion of the impact on hospital libraries of both IAIMS (Integrated Academic Information Management Systems) and JCAHO (Joint Commission on Accreditation of Healthcare Organizations), see Doyle, J.D. (1999). IAIMS and JCAHO: Implications for hospital librarians. *Bulletin of the Medical Library Association 87*(4), 383–386 and Schardt, C. M. (1998). Going beyond information management: Using the Comprehensive Accreditation Manual for Hospitals to promote knowledge-based information services. *Bulletin of the Medical Library Association 86*(4), 504–507.
3. Additional information about the informationist conference is available from the Web site of the Medical Library Association at http://mlanet.org/research/informationist. Accessed November 4, 2002.

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