

Public Access to Health Information: Finding a Balance **An MLA and AAHSL Perspective**

Access to Health Care Information

The Internet and emerging technologies are quickly changing the way that health professionals and the public gain access to health information, raising expectations for access and creating challenges for balancing ownership rights and public access to health care information. This information includes: (1) patient-specific information (e.g., patient health care records); (2) aggregate and comparative data derived from a variety of sources (e.g., NLM genetic databases); and (3) knowledge-based information found in the literature (e.g., research results that support patient care, including consumer health information).

The importance of access to health care information has been underscored by several publications. For example, the *Wall Street Journal*, the *Journal of the American Medical Association*, and *Academic Medicine* have documented that timely access to information helps significantly lower costs and shorten hospital stays [1-4]. The Institute of Medicine (IOM) has reported that even very literate people may have trouble obtaining, understanding, and using health information [5]. The Agency for Healthcare Research and Quality (AHRQ) has concluded that low reading skill and poor health are clearly related [6].

Since their beginnings, the Medical Library Association (MLA) and the Association of Academic Health Sciences Libraries (AAHSL) have been key stakeholders in the creation, dissemination, and preservation of health care information, with a primary focus on knowledge-based information [7-10]. The associations believe that access to information is critical to advancing science and promoting healthy people and that knowledge is indispensable in making informed decisions in health care, education, and research. Health sciences librarians are essential in facilitating a balanced approach that ensures that individual's rights to appropriate, authoritative, easily, and readily accessible health care information and protects the owner's rights, including intellectual property, attribution, recognition, and compensation in a democratic society.

Balancing Rights of Ownership with Need for Access

The public should have the widest possible access to health care information. Likewise, information owners have the right to prevent the unauthorized use or sale of their property. Thus, public policy must recognize fundamental principles associated with information access, distribution, and preservation, especially those pertaining to:

- *Intellectual Freedom*: The right to easy and effective access to health care information from all sources, including rights guaranteed by the First Amendment.
- *Privacy*: The right of all people to anonymity and privacy while retrieving and communicating information, including the right to be fully informed about privacy policies and principles.
- *Intellectual Property*: The right to legal ownership of information resulting from intellectual activity in industrial, scientific, literary, and artistic fields. Public law (copyright) and civil law (licensure) must ensure a fair and equitable balance among

the needs of the public, creators, and owners. The cost to the information user should be fair and equitable and not inhibit access. Authors, creators, and other copyright owners should be provided fair and reasonable incentives for their work.

- *Equitable Access*: The right to health care information access with as few barriers as possible, whether in print and/or electronic formats, and available simultaneously to everyone everywhere.

Advancing Science and Promoting Health People

Making health care information more readily available to the public is vital to the nation's health and furthers research, innovation, and development of knowledge. To provide a return on society's investment in scholarly research, health care information must also be organized, communicated, and preserved for current, historic, and future access by the public.

- *Creating Knowledge*: Creating knowledge is the first step in advancing science.
 - Authors should be appropriately recognized for their intellectual contributions independent of the venue in which the work is disseminated and should assume full responsibility for the rigor and integrity of their work.
 - Experts should scrutinize health care information before it goes public. Peer review, the scientific community's method of quality control, must balance the independent nature of this process and employ safeguards against undue peer pressure and inappropriate political criticism.
 - The dissemination of results should be a recognized part of the cost of conducting research.
- *Accessing Knowledge*: Creating new knowledge is not enough; knowledge must be communicated.
 - People should have access to a rich variety of content that reflects their diverse histories, concerns, and visions of the future.
 - Patients, consumers, and health care providers must have easy access to high-quality and current information and research findings to make sound decisions regarding health status and health care.
 - A robust public domain should include facts, government information, and similar resources whose access is encouraged by the timely cessation of copyright term limits.
 - Existing provisions (for example, fair use and first sale doctrines that allow exemptions for libraries for educational use and promote dissemination of information) must be protected.
 - Expansion of collaboration between the public and private sectors (for example, US government agencies, public health organizations, libraries, publishers, foundations, and societies) for distribution of information should be encouraged.
 - Open access initiatives such as the Budapest Open Access Initiative, BioMed Central, The Scholarly Publishing and Academic Resources Coalition (SPARC), and the Public Library of Science (PLoS) should be encouraged to create and support new scholarly publishing models, to overcome rising costs,

- and to facilitate more rapid and widespread access to the literature, especially information generated from federally funded scientific and medical research.
 - The value-added roles that publishers play in the dissemination of knowledge should be recognized, and new and alternative publishing models for affordable access should be recognized.
- *Preserving Knowledge*: Preservation of knowledge for future generations also plays an important role in advancing science and promoting healthy people.
 - Libraries should play an active role in the management and regulation of technological infrastructures to ensure interoperability and open standards, participation by all in the delivery and creation of content, a secure and private environment, and compatibility between leading edge and trailing edge technologies.
 - The Internet should be used in new ways to develop, distribute, and preserve the historical record of recent major technical and scientific research.
 - New technology legislation should not restrict reasonable uses of content by users, hinder innovation in new systems for delivering information, or impose costs that outweigh the benefits of limited copy protection.

Organizational Biographies

MLA is a nonprofit, educational organization of 900 institutions and 3,600 individual members worldwide who are health sciences information professionals. Through its programs and services, MLA provides lifelong educational opportunities, supports a knowledgebase of health information research, and works with a global network of partners to promote the importance of quality information for improved health to the health care community and the public.
<<http://www.mlanet.org/>>

The Association of Academic Health Sciences Libraries (AAHSL) is comprised of the directors of libraries of 142 accredited US and Canadian medical schools belonging to the Association of American Medical Colleges. <www.aahsl.org>

References

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7. Medical Library Association. Health care reform and the health sciences librarian: excellence in health through access to information. A joint statement of the Medical Library Association and Association of Academic Health Sciences Library Directors. Chicago, IL: The Association, Nov 1993.
8. Ibid.
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<www.mlanet.org/government/appropriations/2004test.html>.
10. Medical Library Association. Links to scholarly publishing initiatives. [Web document]. Chicago, IL. The Association, April 2004 [cited 19 April 2004].
<www.mlanet.org/resources/publish/pub_resources.html#9>.

Additional Resources

American Library Association. Principles for the networked world. [Web document]. Chicago, IL: The Association, Feb 2003. [cited 22 Mar 2004].
<www.ala.org/ala/washoff/washpubs/principles.pdf>.

The principles in this brochure establish a baseline for the ongoing public policy debate by stating the fundamental public policy requirements needed to support and enhance the ability of libraries to serve the public's information needs.

American Library Association. Principles and strategies for the reform of scholarly communication. [Web document]. Chicago: IL: The Association, Jun 2003. [cited 22 Mar 2004]. <www.ala.org/ala/acrl/acrlpubs/whitepapers/principlesstrategies.htm>.
Scholarly communication is the system through which research and other scholarly writings are created, evaluated for quality, disseminated to the scholarly community, and preserved for future use. The system includes both formal means of communication, such as publication in peer-reviewed journals, and informal channels, such as electronic listservs.

BioMed Central. [Web document]. [cited 1 Jul 2004].
<www.biomedcentral.com/home/>.

BioMed Central's portfolio of over 100 journals ranges from the highly selective, general interest *Journal of Biology*, which publishes both online and in print, to a range of specialist online only journals. BioMed Central also publishes Faculty of 1000, the leading literature evaluation service.

Budapest Open Access Initiative. [Web document]. [cited 1 Jul 2004].
<www.soros.org/openaccess/>.

The Budapest Open Access Initiative (BOAI) aims to accelerate progress in the international effort to make research articles in all academic fields freely available on the Internet. The BOAI arises from a meeting convened in Budapest by the Open Society Institute (OSI). The initiative has been signed by the Budapest participants and hundreds of individuals and organizations from around the world, including scientists and

researchers, universities, laboratories, libraries and library organizations, foundations, journals, publishers, and learned societies

National Research Council. [Web document]. [cited 1 Jul 2004]. <www.nas.edu/nrc/>. The National Research Council is part of the National Academies, which also comprise the National Academy of Sciences, National Academy of Engineering, and Institute of Medicine. The research council was organized by the National Academy of Sciences in 1916 to associate the broad community of science and technology with the academy's purposes of further knowledge and advising the federal government. The National Academies Press site <www.nap.edu> provides free electronic access to the full-text of more than 3,000 reports.

Open Archives Initiative. [Web document]. [cited 1 Jul 2004]. <www.openarchives.org>.

The Open Archives Initiative develops and promotes interoperability standards that aim to facilitate the efficient dissemination of content. The Open Archives Initiative has its roots in an effort to enhance access to electronic print archives as a means of increasing the availability of scholarly communication.

Partners in Information Access in the Public Health Workforce. [Web document]. [cited 1 Jul 2004]. <phpartners.org>.

This site includes links to Healthy People 2010 www.healthypeople.gov and other resources as a collaborative project to provide public health professionals with timely, convenient access to information resources to help them improve the health of the American public. This help includes the new HP2010 Information Access Project that provides automatic links to information on Healthy People 2010 objectives. This site lets users launch a preformatted search in PubMed for published literature related to achieving objectives in six Healthy People 2010 chapters or "focus areas."

Public Library of Science (PLOS). [Web document]. [cited 1 Jul 2004]. <www.plos.org>

PLOS is a nonprofit organization of scientists and physicians committed to making the world's scientific and medical literature a freely available public resource. PLOS goals are to (1) open the world's library of scientific knowledge; (2) facilitate research, informed medical practice, and education; and (3) enable scientists, librarians, publishers, and entrepreneurs to develop innovative ways to explore and use the world's treasury of scientific ideas and discoveries.

SPARC. [Web document]. [cited 1 Jul 2004]. <www.arl.org/sparc/>

SPARC is an alliance of academic and research libraries and organizations working to correct market dysfunctions in the scholarly publishing system. Its pragmatic focus is to facilitate the emergence of systems that capitalize on the networked environment and to disseminate research. Its strategies expand competition and support open access to address the high and rising cost of scholarly journals, especially in science, technology, and medicine—a trend which inhibits the advancement of scholarship.

Washington D.C. principles for free access to science: a statement from not-for-profit publishers. [Web document]. 16 Mar 2004. [cited 22 Mar 2204].

<www.aspb.org/publications/dcprinciples.cfm#statement>

Forty-eight nonprofit society publishers affirm their commitment to innovative and independent publishing practices and to promoting the wide dissemination of information in their journals.

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