Linking Medical Librarians and PHRs

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by David Sweet, MLS

Medical librarians are a key source of information on healthcare topics. Their role is expanding with the boom in personal health record (PHR) products. In May 2007 Jean Shipman, president of the Medical Library Association (MLA), and Donald Lindberg, MD, director of the National Library of Medicine (NLM), formed a blue-ribbon task force to survey the current state of personal health records and the role of medical librarians in PHRs.

Coordinated by NLM and MLA, the task force reviewed the current state of PHRs, with a main focus on examining how links to quality health information and medical librarians can be provided from these records. The task force's specific charges were to:

- Determine the key players and providers of the various types of electronic PHRs
- Create an inventory of health information resources to encourage the public to view medical librarians as a source of personal assistance and to use quality Web-based health information resources, especially those offered by NLM
- Define what assistance medical librarians can offer PHR users and provide an assistance qualification statement so users know what services to expect when they contact a medical librarian
- Identify training needs of medical librarians to enable them to support the health information resources contained within PHRs !

Members of the task force included librarians from the National Library of Medicine, Veterans Administration, Kaiser Permanente, Vanderbilt University, Oregon Health and Sciences University, Virginia Commonwealth University, and AHIMA.

Through its work, the task force found that the PHR environment and players are ever changing and that PHRs offer the potential for their users to connect with librarians or library resources through their consumer health information component. Medical librarians can help HIM professionals educate consumers on the importance of PHRs and what information to include.

Surveying the PHR Landscape

One of the first tasks the group undertook was to create a detailed database of electronic PHR products and vendors, especially ones using open-source architecture. The task force defined an electronic PHR as a "private, secure application through which an individual may access, manage and share his health information. The PHR can include information that is entered by the consumer and/or data from other sources such as pharmacies, labs, and health care providers. The PHR may or may not include information from the electronic health record (EHR) that is maintained by the health care provider and is not synonymous with the EHR."

In addition to standard demographic identifiers, the group attempted to capture whether PHRs provided consumer health information or links to consumer health information and if EHR information was included in the PHR.

At the end of 2008 the database included 91 viable PHRs that met the group's electronic PHR definition. The group found 26 nonviable entries that did not meet its definition, were defunct, or were not yet implemented.

The inventoried PHRs varied in sophistication and comprehensiveness. Many are standalone products in which the patient enters all the information, while others are integrated with a provider or insurer's EHR. Only a few PHR vendors provide both integrated and standalone versions of their products, depending on whether the vendor is working directly with a patient or with a healthcare provider.

Most of the PHRs that were examined by the task force operate on Web-based platforms.

Medical Librarians' PHR Roles

The group then conducted an association-wide survey of MLA medical librarians to identify the current roles of librarians as they relate to PHRs. Almost one-third of the respondents were from the Veterans Administration.

The primary roles included:

- Assisting patients in registering for an organizational PHR
- Training patients on how to use an organization's PHR
- Providing staff with information about how PHR use might reduce costs and benefit the institution
- Helping physicians implement a patient portal system, including a PHR

The group then developed an assistance statement that PHR vendors could include with their products. The primary objective was to provide vendors with third-party consumer information sources developed by medical librarians. The statement would ensure consumers receive quality health information at a point where they could easily access it at a time when they needed it, as well as to provide another avenue for consumer health librarians to offer their services. The statement reads:

For quality health information, connect to National Library of Medicine's **MedlinePlus**, http://medlineplus.gov, Resources for Health Consumers, http://www.mlanet.org/resources/consumer_index.html, or a **Top 100**List ranked by medical librarians, http://caphis.mlanet.org/consumer.

Medical librarians can help you with finding other health information. To find a medical librarian near you, call 1-800-338-7657 or view http://nlm.nih.gov/medlineplus.libraries.html. Librarians will not provide personal medical advice, but they will find trusted information about drugs, conditions, procedures, lab tests, and other health topics. 3

The task force wrote a letter to PHR vendors on behalf of NLM and MLA. The letter congratulates them on their PHR product, outlines the work done by the task force, and requests vendors imbed the assistance statement into their products.

So far, three vendors have agreed to use the assistance statement. NLM has also agreed to include portions of the assistance statement in its PHR.

Getting the Word Out

The task force also created a poster that it presented at the 2008 national Medical Library Association conference, numerous regional MLA meetings, and the fall 2008 American Medical Informatics Association meeting. The poster outlines the work of the task force, PHR examples, and the roles that librarians play in PHRs.

Lastly, the task force created PowerPoint slides based on its work, which it offered for health information literacy curriculum. The primary audience is healthcare providers being taught by librarians in a medical school setting. The group also adapted the slides to be included in continuing education courses for librarians to make them aware of PHRs and their role in helping consumers create PHRs.

Although the task force officially disbanded at the end of last year, work will continue through the consumer and patient health information section of the MLA.

Notes

- 1. Medical Library Association. "MLA/NLM Joint Electronic Personal Health Record Task Force Final Report and Recommendations." Available online at www.mlanet.org/about/annual_report/08_09/2008_09_ar_task_forces.pdf.
- 2. Ibid.
- 3. Ibid.

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New Blogs on myPHR.com

AHIMA is adding new features to its PHR Web site, <u>myPHR.com</u>. New blogs go live this month that will focus on parents, athletes, travelers, caregivers, and senior citizens—populations most likely to receive frequent requests for their health information. Members of the AHIMA PHR practice council will author the new blogs. AHIMA's community education coordinators will also contribute.

Visit www.myPHR.com to read these new resources and check out the latest PHR news.

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