Personal Health Records

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Objectives

- Participants will be able to:
  - Define a personal health record.
  - Name at least one role that librarians may have in personal health records.
  - Explain the purpose of the MLA/NLM assistance statement for consumer health information found in participating personal health records.

Definition

- Electronic personal health record (PHR) – 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 care providers. The PHR might or might not include information from the electronic health record (EHR) which is maintained by the health care provider and is not synonymous with the EHR. PHR sponsors include vendors who may or may not charge a fee, health care organizations such as hospitals, health insurance companies, or employers.

Electronic Medical Records

- Official patient records maintained and accessed by health care providers
- May or may not be accessible through personal health records
- May or may not have information transferred into personal health records

Background

- Electronic personal health records (PHRs) are being developed and promoted to encourage individuals to record their health histories with the goals of enhancing the quality of health care and reducing associated costs. There are many groups looking into PHRs' feasibility, technical development, application, interoperability and acceptability.

MLA/NLM Joint Electronic Personal Health Record Task Force

- Appointed April 2007 for one year
- Term extended to December 2008
- Defined personal health record (PHR)
- Reviewed lists of PHRs
- Determined fields to be entered in database
- Online database created at NLM
- Assigned PHRs to task force members for contact and subsequent entry in database
- Reviewed literature on PHRs

MLA/NLM Joint Electronic Personal Health Record Task Force, *cont'd*

- Identified ways to create awareness
  - *MLA News* article
  - *MLA Focus* article
  - Listserv surveys
  - Created slides for inclusion in MLA and NLM courses
  - Created slide for inclusion in health literacy course
  - Worked with leaders of proposal for symposium on PHRs
  - Article for NN/LM newsletters
  - Presented at RML teleconference
  - Posters at chapter meetings and AMIA

- Drafted letter to vendors offering assistance statement to them for incorporation in their PHRS

Data Elements in Database

- Name of company and of its PHR
- Contact information
- Category – independent, care provider, insurer, employer or other
- Standalone, integrated or both
- Open source or proprietary
- Free or fee
- CHI offered
- Platform – Web, PC, Mac

Data Elements in Database, *cont'd*

- Privacy/security measures
- Standards
- Viewing sample available
- Downloadable to mobile device
- Marketplace penetration
- Web access point
- Satisfied users and their comments
- Notes

Types of PHRs

- Integrated with EMR vs independent
- General or specialized
- Accessible on web, on a CD, on a flash drive
- Self-entered, transferred from EMR, or entered by vendor
- Offered by private company, by health care provider, by insurer or by employer

Types of Information in and Features of PHRs

- Allergies
- Conditions
- Prescriptions
- Surgeries
- Immunizations
- Laboratory test results
- Tracking of blood pressure, weight, blood sugar
- Appointments
- Messaging with health care providers
- Family history

Librarians' Roles

- Assisting patients in enrolling in PHRs (My HealtheVet, Kaiser Permanente)

- Educating/training employees in use of an organization's PHR (My HealtheVet)
- Providing consumer health information as result of links in PHRs
- Providing staff with information about PHRs—how they might reduce costs, inform consumers and benefit the institution
- Providing training on the UMLS and how it can be integrated into PHRs
- Incorporating information about PHRs into academic courses
- Evaluating and selecting consumer health content to be included in PHRs
- Helping implement patient portals that include PHRs
- Endorsing use of PHRs through consumer outreach efforts to build trust and acceptance
- Assisting health care providers in adopting use of PHRs

Assistance Statement Development

- Drafted by MLA/NLM PHR Task Force
- Vetted by plain language expert
- Offered to several PHR vendors as means of connecting PHR users with medical librarians and with NLM and MLA CHI resources
- Accepted by several PHR vendors
- More vendors being contacted

Assistance Statement

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

- Medical librarians can help you find other health information. To find a medical librarian near you, call **1-800-338-7657** or view http://www.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.

Vendors Who Have Agreed to Incorporate the Assistance Statement

- Access Strategies
  - FollowMe
  - MiVIA
- Medem
  - iHealthRecord
- Tolven Healthcare Innovations
  - ePHR

Based on the success of these responses, more letters will go out under signature of the MLA President and NLM Director to ask additional PHR vendors if they would be interested in incorporating the assistance statement into their PHR products.

Findings
Standalone or Integrated

- 117 PHRs were examined.
- Almost half (49%) of the PHRs are standalone products. All information in them is entered by the consumer.
- 29% are integrated while 12% are both standalone and integrated. Vendors who offer "both" standalone and integrated products either work directly with patients OR with health care providers who, in turn, make the products available to their patients.

Findings
Consumer Health Information in PHRs

- 50% of those examined by MLA/NLM Joint Electronic Personal Health Record Task Force include consumer health information (CHI).
- Most common sources of CHI in PHRs:
  - MedlinePlus
  - Healthwise
  - Medical societies/organizations
  - PHR vendor’s developed content

Findings
PHR Standards

- A number of the PHRs already use particular standards and may employ more than one standard. Others have stated that they are watching the development of the standards and will adopt them in the future. Some of the existing standards are related to the structure of the records; others are related to nomenclature. National standards will be a necessity for interoperability, transportability and security of electronic health records and personal health records.

Findings
PHR Standards

Standard	**# of PHRs**
CCD (Continuity of Care Document)	5
CCR (ASTM Continuity of Care Record)	16
CDA (Clinical Document Architecture) [part of HL-7]	1
DICOM (Digital Imaging & Communications in Medicine)	1
GEHR (Good Electronic Health Record)	1

Findings
PHR Standards, *cont'd*

Standard	**# of PHRs**
HL-7 (Health Level Seven)	11
ICD-9-CM/ICD-10	1
SNOMED (Systemized Nomenclature of Medicine)	2
UMLS (Unified Medical Language System)	2

Findings
PHRs on Mobile Devices

- 39 PHRs are available for mobile devices.
- Of those 39, only 6 are downloadable from the Web.

Some PHRs are initially sold as mobile devices, such as flash drives that are incorporated into bracelets or wallet cards.

Findings
Privacy and Security

Security is an important issue for the private information in PHRs. Many of the web-based products use Secure Socket Layer (SSL) to enable encryption. A number of these specify the VeriSign certificate authority. While the vendor representatives sometimes could not name any security mechanisms beyond requiring password access, others mentioned protected servers, firewalls, and HIPAA compliance. Some systems allow the user to select a family member and/or a health care provider who may be permitted to view their information.

Conclusions

- The personal health record is a rapidly evolving, dynamic area of health informatics.
- A number of organizations are studying these developments: AARP, AHIMA, AHIP, Chilmark, HIMSS, National Library of Medicine, Robert Wood Johnson Foundation, Markle Foundation, etc.
- The visibility of PHRs has been raised by Google and Microsoft jumping into the market.
- As of February 16, 2009, there are almost 200 citations in PubMed on personal health records.
- PHRs have been the subject of presentations at a number of conferences held by library, medical informatics, health information management and health information technology groups.

Future

- PHRs that survive will be the ones that conform to CCR, CCD, HL7, ICD-9, SNOMED, and other developing standards.
- More patient knowledge/more patient control, i.e., patient empowerment
- “Buy in” and recognition by physicians
- Portability and interoperability
- Regulations and laws to insure standards, privacy and security
- Certification of elements such as privacy, security, portability/interoperability, and functionality.

Quote

- "While PHRs are no panacea for the healthcare challenges this country faces, they have the potential to initiate change that is long overdue, change that will be consumer led and consumer driven." –John Moore, Founder & Managing Director, Chilmark Research. *PHR Market Report: Analysis & Trends of Internet-based Personal Health Records' Market*. Chilmark Research, 2008.

References

- Halamka JD, Mandl KD, Tang PC. Early experiences with personal health records. J Am Med Inform Assoc. 2008 Jan-Feb;15(1):1-7.
- Kaelber DC, Jha AK, Johnston D, Middleton B, Bates DW. A research agenda for personal health records (PHRs). J Am Med Inform Assoc. 2008 Nov-Dec;15(6):729-36.
- Reti SR, Feldman HJ, Safran C. Governance for personal health records. J Am Med Inform Assoc. 2009 Jan-Feb;16(1):14-7.
- Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. J Am Med Inform Assoc. 2006 Mar-Apr;13(2):121-6.

Web References

- Chilmark Research. iPHR market report: analysis & trends of Internet-based personal health records' market. Executive Summary. Chilmark Research, 2008. Available from: http://www.chilmarkresearchstore.com/iphr2008execsummary.html
- Cronin C. Personal health records: an overview of what is available to the public. AARP, 2006. Available from: http://www.chilmarkresearchstore.com/iphr2008execsummary.html
- Kaelber DC, Shah S, Vincent A, et al. Center for Information Technology Leadership. The value of personal health records. Healthcare Information and Management System Society, 2008. Available from: http://www.citl.org/_pdf/CITL_PHR_Report.pdf
- Lake Research Partners and American Viewpoint. Survey finds Americans want electronic personal health information to improve own health care. Markle Foundation, 2006. Available from: http://www.markle.org/downloadable_assets/research_doc_120706.pdf

Thank you!

- Questions?

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