Personal Health Records, 63 citations and selected News items 4/6/2007
Compiled by Catherine Selden and Marcia Zorn, NLM

Definitions

Markle Foundation's Connecting for Health collaborative http://connectingforhealth.org/ defined PHR as:
"An electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment."

American's Health Insurance Plans (AHIP)
http://www.ahip.org/content/fileviewer.aspx?docid=18328&linkid=156982 defined PHR as:
The industry model personal health record (PHR) is a private, secure web-based tool maintained by an insurer that contains claims and administrative information. PHRs may also include information that is entered by consumers themselves, as well as data from other sources such as pharmacies, labs, and care providers. PHRs enable individual patients and their designated caregivers to view and manage health information and play a greater role in their own health care. PHRs are distinct from electronic health records, which providers use to store and manage detailed clinical information.

Recent News Items

Personal health records would empower patients, boost care quality, and reduce costs according to Rep. Patrick Kennedy (D-.I.) and Rep. Dave Reichert (R-Wash.) http://thehill.com/leading-the-news/personal-health-records-would-empower-patients-boost-care-quality-reduce-costs-2007-03-27.html "March 27, 2007. Last month, we introduced a new version of the Personalized Health Information Act. This legislation will empower consumers to be better informed about their personal health while improving communication with their healthcare providers" .. Our bill would require that the secretary of Health and Human Services create a personal health record incentive program and trust fund to expedite the use of personal health records by Medicare beneficiaries and other patients and their healthcare providers. PHRs can give patients access to and control over their personal health data while ensuring that providers have all of the information they need at the point of care if the patient consents. The bill is viewed by industry experts as a necessary first step toward the adoption of a nationwide electronic medical records system.

Many U.S. adults are satisfied with use of their personal health information according to a Harris Poll. March 26, 2007
While many U.S. adults indicate that they are generally satisfied with how their personal health information is used, a substantial number has serious reservations about the confidentiality and security of their health data. One in six adults (17%) – representing about 38 million persons – say they withhold information from their health providers due to worries about how the medical data might be disclosed. These are some of the results of a nationwide Harris Poll of 2,337 U.S. adults surveyed online between January 11 and 18, 2006 by Harris Interactive. This survey was designed in collaboration with Dr. Alan F. Westin, Professor of Public Law and Government Emeritus at Columbia University and a noted authority on current health privacy issues, especially those involving electronic health record programs. http://www.harrisinteractive.com/harris_poll/index.asp?PID=743

America's Health Insurance Plans, Blue Cross and Blue Shield Association and Aetna
http://www.bcbs.com/news/bcbsa/industry-leaders-announce-phr-model.html announced that they were collaborating to create a Web-based PHR by 2008. The model PHR will include medical histories, medications, immunizations, allergies, risks, and care plans and will be maintained by insurers but portable across different plans. Dr. I-Net Corporation will provide an electronic Personal Health Record (PHR) to BCBS 4.6 million covered FEP Members.

Five major U.S. companies, Intel, Wal-Mart, Pitney-Bowles, British Petroleum-America Inc., and Applied Materials, announced in December that they will offer health records to a combined 2.5 million employees, retirees, and their families by mid-2007. Individuals will control their own health records, sharing information with providers and other parties as they choose. The shared health record technology, called Dossia, will be developed and hosted by Omnimedix Institute, a Portland, Ore. –based nonprofit organization and the five employers will not have access to users' personal health information .

Aetna introduces powerful, interactive Personal Health Record http://www.aetna.com/news/2006/pr_20061003.htm powered by ActiveHealth's patented CareEngine® System. Aetna's Personal Health Record provides personalized alerts to members and physicians about opportunities to improve care. It will provide members with online access to personal information, including detailed health history, and integrated information and resources to help members make informed decisions about their health care. The CareEngine-powered PHR automatically combines detailed, claims-driven information gathered across the health care spectrum - such as physician office, lab, diagnostic treatment and prescriptions – to generate a comprehensive personal health record.

A new report was issued in January 2007 entitled Review of the Personal Health Record (PHR) Service Provider Market: Privacy and Security providing http://www.hhs.gov/healthit/ahic/materials/01_07/ce/PrivacyReview.pdf

Sens. Tom Carper, D-Del., and George Voinovich, R-Ohio**,** today introduced legislation that would promote the use of electronic personal health records within the health care industry. September 6, 2006 http://voinovich.senate.gov/news_center/record.cfm?id=262491

Other Examples of PHRs

CapMed® PHR provides its user manual online at http://www.capmed.com/pdfs/PHR_4.5_Help.pdf
My HealtheVet http://www.myhealth.va.gov/
TeleMedical.Com's TelemedicalRecord.com, Your Guide to Electronic Health Records, Community Care Records,and Personal Health Records. http://www.telemedicalrecord.com/

Background Articles

The Stead (citation 57 http://arjournals.annualreviews.org/doi/abs/10.1146/annurev.med.58.061705.144942) and Tang (citation 58 - http://www.jamia.org/cgi/content/full/13/2/121) articles offer good overviews of the current status of PHRs in the US. Taneya's article at http://www.pubmedcentral.nih.gov/articlerender.fcgi?tool=pubmed&pubmedid=17252070 explains how the library is part of the team working on PHRs at Vanderbilt.

Citations

1. Albright B. Prepping for PHRs. The growing trend of consumer empowerment includes the speedy rise of personal health records. Healthc Inform. 2007 Feb;24(2):44, 46. Available from: PMID: 17370879

2. American Health Information Management Association, American Medical Informatics Association. The value of personal health records. A joint position statement for consumers of healthcare. J AHIMA. 2006 Oct;77(9):24. Available from: PMID: 17111904
   SUBJECT HEADINGS: *Consensus\Consumer Participation\Hospital Information Systems/organization & administration\Humans*Medical Records\Societies\United States

3. Baker DB, Masys DR. PCASSO: a design for secure communication of personal health information via the internet. Int J Med Inform. 1999 May;54(2):97-104. Available from: PMID: 10219949

ABSTRACT: The Internet holds both promise and peril for the communications of person-identifiable health information. Because of technical features designed to promote accessibility and interoperability rather than security, Internet addressing conventions and transport protocols are vulnerable to compromise by malicious persons and programs. In addition, most commonly used personal computer (PC) operating systems currently lack the hardware-based system software protection and process isolation that are essential for ensuring the

integrity of trusted applications. Security approaches designed for electronic commerce, that trade known security weaknesses for limited financial liability, are not sufficient for personal health data, where the personal damage caused by unintentional disclosure may be far more serious. To overcome these obstacles, we are developing and evaluating an Internet-based communications system called PCASSO (Patient-centered access to secure systems online) that applies state of the art security to health information. PCASSO includes role-based access control, multi-level security, strong device and user authentication, session-specific encryption and audit trails. Unlike Internet-based electronic commerce 'solutions,' PCASSO secures data end-to-end: in the server; in the data repository; across the network; and on the client. PCASSO is designed to give patients as well as providers access to personal health records via the Internet.
SUBJECT HEADINGS: *Computer Security*Confidentiality\Humans*Internet\Medical Records Systems, Computerized/*standards\Software

4. Ball MJ, Gold J. Banking on health: Personal records and information exchange. J Healthc Inf Manag. 2006 Spring;20(2):71-83. Available from: PMID: 16669591

ABSTRACT: Consumer demand for personal health records (PHRs) and the capabilities provided by regional health information organizations (RHIOs) will change healthcare, just as automatic teller machines have changed banking. The PHR is predicated on the existence of electronic medical records (EMRs) and electronic health records (EHRs). Patient and consumer principles guiding the development of the PHR reflect issues of access, control, privacy, and security. Working models illustrate the variations of RHIOs and PHRs possible and suggest the benefits that electronic information exchange can accrue for healthcare and healthcare consumers. Today both the private and public sectors are working to define the issues involved in efforts that are now taking place and that will transform healthcare. Consumers are ready for the type of changes that will improve healthcare quality.
SUBJECT HEADINGS: *Geographic Information Systems\Humans*Medical Record Linkage*Medical Records Systems, Computerized\Models, Organizational\United States

5. Ball MJ, Smith C, Bakalar RS. Personal health records: empowering consumers. J Healthc Inf Manag. 2007 Winter;21(1):76-86. Available from: PMID: 17299929

ABSTRACT: By empowering consumers, electronic personal health records (ePHRs, more commonly PHRs) will play a key role in the evolving electronically enabled health information environment. Consumers want to be more engaged in their own healthcare and are seeking out information online. Despite intense concerns about confidentiality and security, they have high expectations for electronic health information. The growth of patient self-management tools for remote monitoring will fuel PHR adoption, if tools and standards are developed that make clinical information understandable to and usable by consumers. The value of the PHR will lie in shared information and shared decision-making, as its components support the continuity of care. Efforts in other countries can provide guidance in helping Americans do what they do best-develop and use innovative technology to serve the American people.
SUBJECT HEADINGS: *Consumer Participation\Humans*Medical Records Systems, Computerized\United States

6. Black D. Personal health records. J Med Ethics. 1992 Mar; 18(1):5-6. Available from: PMID: 1573654
SUBJECT HEADINGS: Beneficence\Biomedical Research*Confidentiality*Ethics, Medical\Humans*Informed Consent\Medical Records/*standards*Patient Access to Records*Patient Rights\Personal Autonomy\Social Justice

7. Blechner B, Butera A. Health Insurance Portability and Accountability Act of 1996 (HIPAA): a provider's overview of new privacy regulations. Conn Med. 2002 Feb;66(2):91-5. Available from: PMID: 11908191

ABSTRACT: When it enacted The Health Insurance Portability and Accountability Act of 1996, Congress mandated establishment of privacy regulations covering individual health information. Title II of HIPAA, the Privacy Rule that became effective on April 14, 2001, offers Americans the first-ever set of comprehensive protections against the unintended and/or inappropriate disclosure of personal health information. Provisions of the Privacy Rule and its associated regulations include patient control over the use of health information, patient rights to information on the disclosure policies of the health-care provider, patient rights to review and amend one's medical information, standards for limiting the scope of data disclosed to other health-care providers, and penalties for noncompliance with the law. This paper presents a summary of the need for protection of personal health information and an overview of the provisions of this legislative foundation for

protecting personal health records--the HIPAA Privacy Rule.
SUBJECT HEADINGS: Confidentiality/*legislation & jurisprudence\Health Insurance Portability and Accountability Act/*legislation &\jurisprudence\Humans\United States

8. British Medical Association. Annual report of Council, 1985-1986: medical ethics. Br Med J (Clin Res Ed). 1986 Mar 29;292(6524):suppl 25-7. Available from: PMID: 11652461
SUBJECT HEADINGS: Adolescent\Advertising\Confidentiality\Contraception\Ethics Committees\Ethics Committees, Research*Ethics, Medical\Great Britain\Human Experimentation\Humans\Informed Consent\International Cooperation\Internationality\Law Enforcement\Legislation\Medical Records\Minors*Organizational Policy\Parental Notification\Parents\Patient Access to Records\Patient Advocacy\Patient Rights\Physician-Patient Relations\Physicians\Politics\Prisoners\Public Policy\Social Control, Formal\Societies\Substance-Related Disorders\Torture

9. Burrington-Brown J. The PHR effect. J AHIMA. 2005 Feb; 76(2):58-9. Available from: PMID: 15739956
SUBJECT HEADINGS: Awareness\Confidentiality\Data Collection\Humans\Liability, Legal*Medical Record Linkage*Medical Records Systems, Computerized*Policy Making\United States

10. Burrington-Brown J, Friedman B . Educating the public about personal health records. J AHIMA. 2005 Oct;76(9):94-5. Available from: PMID: 16274211. SUBJECT HEADINGS: *Health Education\Information Dissemination*Medical Records\Teaching\United States

11. Clarke JL, Meiris DC, Nash DB. Electronic personal health records come of age. Am J Med Qual. 2006 May-Jun;21(3 Suppl):5S-15S. Available from: PMID: 16621927 SUBJECT HEADINGS: *Diffusion of Innovation\Europe*Medical Records Systems, Computerized\United States

12. Computerisation of personal health records. Health Visit. 1978 Jun;51(6):227. Available from: PMID: 248054 SUBJECT HEADINGS: Computers*Confidentiality\Great Britain*Medical Records

13. Conn J. McKesson deal gives docs new PHR purveyor. Even with acquisition, RelayHealth exec vows vendor neutrality; others dubious. Mod Healthc. 2006 Jun 19;36(25):54. Available from: PMID: 16827480
SUBJECT HEADINGS: Health Care Sector/*trends*Insurance, Health, Reimbursement*Medical Records Systems, Computerized*Patient Identification Systems*Systems Integration\United States

14. Conn J. Personal and (maybe) confidential. Questions over privacy, formats and definitions remain, but personal health records are on the way. Mod Healthc. 2006 Jul 3-10;36(27):28-31. Available from: PMID: 16898550 SUBJECT HEADINGS: Advisory Committees\Computer Security\Confidentiality\Consensus\Emergency Medical Tags\Humans\Medical Records Systems, Computerized/*classification*Patient Access to Records\Patient Identification Systems\Pilot Projects*Program Development*Systems Integration\United States\United States Centers for Medicare and Medicaid Services

15. Connecting for Health. Connecting Americans to their health care: a common framework for networked personal health information. Markle Foundation. 2006; Available from: http://connectingforhealth.org/commonframework/docs/P9_NetworkedPHRs.pdf

16. Cooke T, Watt D, Wertzler W, Quan H. Patient expectations of emergency department care: phase II--a cross-sectional survey. CJEM. 2006 May;8(3):148-57. Available from: PMID: 17320008
ABSTRACT: OBJECTIVES: To explore emergency department (ED) patient expectations regarding staff communication with patients, wait times, the triage process and information management. METHODS: We conducted a cross-sectional English-language telephone survey among patients aged 18 years or older who visited the EDs in the Calgary Health Region in 2002. Survey items were based on a preceding qualitative study. RESULTS: Of the 941 surveys, 837 were analyzed. Patients placed the highest importance on the explanation of test results (96.5%), a description of circumstances that would require the patient to return to the ED (94.4%), the use of plain language (92.1%) and the reason for the tests (90.8%). Seventy-six percent of patients felt that ED staff should update patients every 30 minutes or less, 51.3% expected patients with non-life threatening problems should wait <1 hour, and 58.3% expected that the tests should be done within 1

hour. Almost two-thirds of the patients (64.4%) believed that the most serious patients should be seen first; 59.3% felt that the seriousness of medical concern should be determined by a triage nurse, and 63.9% thought that their personal health records should be immediately available to the emergency physician without their consent. The actual length of stay was significantly longer than expected length of stay for all patient groups, with Canadian Emergency Department Triage and Acuity Scale Levels IV and V patients expecting a shorter wait than patients in more urgent triage groups. Triage level effects on other expectations were not observed. CONCLUSIONS: ED patient expectations appear to be similar across all triage levels. Patients value effective communication and short wait times over many other aspects of care. They have expectations for short wait times that are met infrequently and are currently unattainable in many Canadian EDs. Although it may be neither feasible nor desirable to meet all patient expectations, increased focus on wait times and staff communication may increase both ED efficiency and patient satisfaction.

17. Denton IC. Will patients use electronic personal health records? Responses from a real-life experience. J Healthc Inf Manag. 2001 Fall;15(3):251-9. Available from: PMID: 11642143

ABSTRACT: The Department of Health and Human Services identifies the electronic personal health record (EPHR) as a fundamental "dimension" of a future national health information infrastructure. Currently thirty-some EPHRs are available on the market. Though the potential advantages for clinical care, patient education, and administrative streamlining are highly touted, they remain speculative, and the core question remains: Will consumers actually use EPHRs? Upon retirement in July 1999, the author provided 330 patients a commercial EPHR containing clinical office records from the practice's EMR. One year later, he conducted a mail-in survey that posed a series of relevant yes-and-no questions regarding usage and invited narrative comment and anonymous responses. This article tabulates the results and synopsizes patients' opinions. It provides considerable enlightenment regarding patients, who, among other responses, intended to begin or continue keeping records, used the EPHR on medical visits, would rather not store health information on the Internet, wished to use e-mail with the doctor's office, believed doctors do not keep full records, and strongly believed individuals should keep their own records.
SUBJECT HEADINGS: *Access to Information\Alabama\Attitude to Health\Computer Security\Confidentiality\Humans\Internet/*utilization\Medical Records Systems, Computerized/*utilization\Patient Satisfaction/*statistics & numerical data\Questionnaires

18. Dorr D, Bonner LM, Cohen AN, Shoai RS, Perrin R, Chaney E, Young AS. Informatics Systems to Promote Improved Care for Chronic Illness: A Literature Review. J Am Med Inform Assoc. 2007 March-April;14(2):156-163. Available from: PMID: 17213491

ABSTRACT: OBJECTIVE To understand information systems components important in supporting team-based care of chronic illness through a literature search. DESIGN Systematic search of literature from 1996-2005 for evaluations of information systems used in the care of chronic illness. MEASUREMENTS The relationship of design, quality, information systems components, setting, and other factors with process, quality outcomes, and health care costs was evaluated. RESULTS In all, 109 articles were reviewed involving 112 information system descriptions. Chronic diseases targeted included diabetes (42.9% of reviewed articles), heart disease (36.6%), and mental illness (23.2%), among others. System users were primarily physicians, nurses, and patients. Sixty-seven percent of reviewed experiments had positive outcomes; 94% of uncontrolled, observational studies claimed positive results. Components closely correlated with positive experimental results were connection to an electronic medical record, computerized prompts, population management (including reports and feedback), specialized decision support, electronic scheduling, and personal health records. Barriers identified included costs, data privacy and security concerns, and failure to consider workflow. CONCLUSION The majority of published studies revealed a positive impact of specific health information technology components on chronic illness care. Implications for future research and system designs are discussed.

19. Edlin M. Implementing personal health records. AHIP Cover. 2006 Mar-Apr;47(2):14-6, 19. Available from: PMID: 16700448 SUBJECT HEADINGS: *Diffusion of Innovation\Medical Record Linkage\Medical Records Systems, Computerized/*utilization\United States

20. Endsley S, Kibbe DC, Linares A, Colorafi K. An introduction to personal health records. Fam Pract Manag. 2006 May;13 (5):57-62. Available from: PMID: 16736906 SUBJECT HEADINGS: Family Practice/*organization & administration\Humans*Information Systems\Medical Record Linkage*Medical

Records Systems, Computerized*Patient Access to Records\Patient Identification Systems\Systems Integration\United States

21. Gawthorn EC. Personal health records (PHR). Aust Fam Physician. 1983 Jun ;12(6):466-8. Available from: PMID: 6626044 SUBJECT HEADINGS: Humans*Medical Records*Self Care

22. Harman LB. HIPAA: a few years later. Online J Issues Nurs. 2005 May 31;10(2):3. Available from: PMID: 15977976

ABSTRACT: This article addresses the impact of the Health Insurance Portability and Accountability Act (HIPAA) several years after implementation. The rationale for HIPAA and a clarification of key terms, including covered entities, personal health information, and designated record sets, is reviewed. The impact of HIPAA at work, including increased cost and the complexities of educating employees and patients is assessed. Implications for homeland security, disaster planning, unique patient identifiers, the compilation of personal health records, and research are discussed.
SUBJECT HEADINGS: Attitude of Health Personnel\Confidentiality/*legislation & jurisprudence/*trends\Cost-Benefit Analysis\Education, Nursing, Continuing*Health Insurance Portability and Accountability Act/economics\Humans\Medical Informatics Applications\Patient Education\Terminology\United States

23. Hicks J. Advocating for the PHR: educator's work sets stage for the future. J AHIMA. 2005 Nov-Dec;76(10):88. Available from: PMID: 16333952 SUBJECT HEADINGS: *Consumer Advocacy\Female\Humans\Medical Record Administrators/education*Medical Records Systems, Computerized\Teaching\United States

24. Iakovidis I. From electronic medical record to personal health records: present situation and trends in European Union in the area of electronic healthcare records. Medinfo. 1998;9 Pt 1:suppl 18-22. Available from: PMID: 10384547

ABSTRACT: In this article we define the electronic healthcare record (EHR) and present its purpose as a tool for continuity of care. We consider the EHR system as a necessary tool for collaborative work of healthcare professionals linking the traditional stand alone physician's systems or departmental systems, which we refer to here as electronic medical record systems. We briefly describe the current usage of electronic medical records in EU and focus on the major challenges to wide implementation of electronic healthcare record systems. Finally, we point out trends that show stronger involvement of patients (citizens) in the health care process and discuss the impact on future EHR systems. We call the next generation of EHR that takes into account the new role of citizens Personal Health Records.
SUBJECT HEADINGS: Confidentiality\Consumer Satisfaction\European Union\Forecasting\Humans\Medical Record Linkage*Medical Records Systems, Computerized/standards/statistics & numerical\data/trends/utilization

25. Iakovidis I. Towards personal health record: current situation, obstacles and trends in implementation of electronic healthcare record in Europe. Int J Med Inform. 1998 Oct-Dec;52(1-3):105-15. Available from: PMID: 9848407

ABSTRACT: In this article, we define the electronic healthcare record and present its purpose as a tool for continuity of care. We briefly describe the current situation of usage and focus on the major challenges to wide implementation in Europe and beyond. Finally, we point out trends that show stronger involvement of the patients-citizens in the health care prevention and promotion processes, and discuss the impact on the future development of the electronic healthcare record into personal health records. SUBJECT HEADINGS: Computer Systems*Continuity of Patient Care\Databases\Europe\Forecasting\Humans*Medical Records Systems, Computerized*Telemedicine\Terminology

26. Information prescriptions (Ix): bringing internet-based health content into the treatment process, patients to your site. Internet Healthc Strateg. 2005 Apr;7(4):4-8. Available from: PMID: 15929640

ABSTRACT: Information therapy is a process in which clinicians recommend specific Web content to their patients. Systems can be highly automated and used in conjunction with patient portals, electronic medical records, personal health records, or insurance company claims databases. Or they can be manual and informal on the prescriber's end, where doctors simply recommend specific URLs to their patients. With careful

coordination, any of them can bring more patients to a healthcare Web site.
SUBJECT HEADINGS: Cost Control\Disease Management\Guideline Adherence\Guidelines\Humans\Information Dissemination/*methods\Insurance Claim Reporting*Internet*Patient Participation\United States

27. Jeffs D, Harris M. The personal health record. Making it work better for general practitioners. Aust Fam Physician. 1993 Aug;22(8):1417-9, 1421, 1424-7. Available from: PMID: 8379881

ABSTRACT: Personal Health Records held by parents are an important initiative towards improved child health in Australia. Although they have now been introduced in most States and Territories, few general practitioners make full use of them. A recent major study conducted in New South Wales suggests ways in which their use and usefulness can be improved for general practitioners.
SUBJECT HEADINGS: Attitude of Health Personnel\Child\Data Collection*Family Practice\Humans*Medical Records

28. Jeffs D, Nossar V, Bailey F, Smith W, Chey T. Retention and use of personal health records: a population-based study. J Paediatr Child Health. 1994 Jun;30(3):248-52. Available from: PMID: 8074911

ABSTRACT: A parent-held record has been issued to all children born in New South Wales (NSW), Australia since 1988. Five years after its introduction, an evaluation was undertaken to determine its retention rate over time, rate of documentation of immunization status and other important child health information, and its perceived usefulness to parents. The cross-sectional study comprised an interviewer administered questionnaire to 622 households derived from a stratified random sample of 25 local government areas, representative of 73% of all households containing children under 5 years of age in NSW. A concurrent postal survey assessed the attitudes and use of the Personal Health Record (PHR) among a stratified random sample of 911 health care providers. Results showed that the PHR was well retained, with 89% claimed retention at 4 years, and over 78% of parents able to produce the record for inspection at interview. Of the records examined, 91% had at least one immunization recorded while 68% had a complete regimen documented by age 4 years. Overall, 93% of parents expressed satisfaction with the PHR, while 64% of all health care providers also felt that the PHR was 'beneficial to the health care children received', although only 53% of these used it regularly to record their findings. It is concluded that the PHR currently issued in NSW is well retained and valued by parents, and used by and useful to a range of health professionals.
SUBJECT HEADINGS: Attitude of Health Personnel\Attitude to Health\Child Health Services/*utilization\Child, Preschool\Cross-Sectional Studies\Humans\Immunization\Infant\Infant, Newborn*Medical Records\New South Wales\Parents/*psychology*Patient Compliance\Patient Satisfaction\Questionnaires

29. Joshi P, Jones KV, Hanson RM, Alperstein G, Fasher B. Personal health records. J Paediatr Child Health. 1993 Oct;29(5):400-1. Comment on: J Paediatr Child Health. 1993 Apr;29(2):150-3. PMID: 8489797. Available from: PMID: 8240876 SUBJECT HEADINGS: Child, Preschool*Health Knowledge, Attitudes, Practice\Humans*Medical Records\New South Wales*Parents

30. Jossi F. Personal health records. Healthc Inform. 2006 Feb;23(2):52, 54. Available from: PMID: 16597007
SUBJECT HEADINGS: Humans*Medical Records*Patient Participation\United States

31. Kanaan S, Burke-Bebee S, Rippen HE. A Report on Three Consumer Focus Group Meetings . Consumer control of electronic personal health information: what does it mean? why is it important? Prepared for Office for Science and Data Policy, Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services. Mar. 1, 2006. Available from: http://aspe.hhs.gov/sp/07/consumer/index.htm

ABSTRACT: Public and private health care sectors recognize that health information technology (HIT) plays a pivotal role for improving health care quality while reducing health care cost. Many new initiatives have created a momentum greater than in the past for adopting electronic health records (EHRs) and HIT in general. In the current environment, the principle that the patient and consumer control their personal health information (PHI) is frequently invoked and linked to the broader principle of patient-centricity. Surveys by the Markle Foundation and the California Health Care Foundation confirm that most consumers are concerned about the privacy and security of their PHI. While many consumers recognize the benefits of EHRs and other

forms of HIT, they want and expect to control access of their PHI—who sees it, what they see and under what conditions.
Several organizations such as the Consumers Union, Health Privacy Project, and National Consumers League support a set of consumer-focused principles for designing a nationwide electronic health infrastructure1. An immediate challenge persists in defining what control means to the consumer and soliciting consumer engagement in workable solutions as the industry plans for HIT implementation. To this end, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) within the Office of the Secretary at the Department of Health and Human Services hosted three consumer focus group meetings in October 2005 for day-long discussions on these topics. Health Services Research and Shugoll Research recruited the participants.

32. Kim E, Mayani A, Modi S, Kim Y, Soh C. Evaluation of patient-centered electronic health record to overcome digital divide. Conf Proc IEEE Eng Med Biol Soc. 2005;2:1091-4. Available from: PMID: 17282378

ABSTRACT: Advances and wide acceptance of information and communication technology (ICT) have made development and implementation of web-based electronic personal health records (PHRs) more feasible than ever before, and previous studies have demonstrated some of its potential and promises. However, this type of ICT-dependent approach inherits its own vulnerabilities of exposing the society to digital divide, commonly described as the gap that exists among individuals and communities with regards to the haves and have-nots of information and modern communications technologies. To address these concerns and improve healthcare outcomes, we have developed and customized a web-based patient-centered electronic PHR, named the Personal Health Information Management System (PHIMS), and evaluated the system at the Everett Housing Authority, which provides housings for low-income ncome families and elderly or disabled populations. A preliminary study demonstrates that 92% of the participating residents are satisfied with the PHIMS system in general. Some of the residents found PHIMS records very useful for their clinic visits.

33. Kim MI, Johnson KB. Patient entry of information: evaluation of user interfaces. J Med Internet Res. 2004 May 14;6(2):e13. Comment in: J Med Internet Res. 2004 May 20;6(2):e14. PMID: 15249263. Available from: PMID: 15249262

ABSTRACT: BACKGROUND: Personal health records are web-based applications that allow patients to directly enter their own data into secure repositories in order to generate accessible profiles of medical information. OBJECTIVE: The authors evaluated a variety of user interfaces to determine whether different types of data entry methods employed by Personal health records may have an impact on the accuracy of patient-entered medical information. METHODS: Patients with disorders requiring treatment with thyroid hormone preparations were recruited to enter data into a web-based study application. The study application presented sequences of exercises that prompted free text entry, pick list selection, or radio button selection of information related to diagnoses, prescriptions, and laboratory test results. Entered data elements were compared to information abstracted from patients' clinic notes, prescription records, and laboratory test reports. RESULTS: Accuracy rates associated with the different data entry methods tested varied in relation to the complexity of requested information. Most of the data entry methods tested allowed for accurate entry of thyroid hormone preparation names, laboratory test names, and familiar diagnoses. Data entry methods that prompted guided abstraction of data elements from primary source documents were associated with more accurate entry of qualitative and quantitative information. CONCLUSIONS: Different types of data entry methods employed by Personal health records may have an impact on the accuracy of patient-entered medical information. Approaches that rely on guided entry of data elements abstracted from primary source documents may promote more accurate entry of information.
SUBJECT HEADINGS: 7488-70-2 (Thyroxine)\Drug Administration Schedule\Graves Disease/diagnosis/drug therapy\Humans\Internet/*standards\Medical Records/*standards\Patient Participation/*methods\Prescriptions, Drug/*standards\Thyroiditis, Autoimmune/diagnosis/drug therapy\Thyroxine/administration & dosage/therapeutic use*User-Computer Interface

34. Kim MI, Johnson KB. Personal health records: evaluation of functionality and utility. J Am Med Inform Assoc. 2002 Mar-Apr;9(2):171-80. Available from: PMID: 11861632

ABSTRACT: OBJECTIVES: Web-based applications have been developed that allow patients to enter their own

information into secure personal health records. These applications are being promoted as a means of providing patients and providers with universal access to updated medical information. The authors evaluated the functionality and utility of a selection of personal health records. DESIGN: A targeted search strategy was used to identify eleven Web sites promoting different personal health records. Specific criteria related to the entry and display of data elements were developed to evaluate the functionality of each PHR. Information abstracted from an actual case was used to create a series of representative PHRs. Output generated for review was evaluated to assess the accuracy and completeness of clinical information related to the diagnosis and treatment of specific disorders. RESULTS: The PHRs selected for review employed data entry methods that limited the range and content of patient-entered information related to medical history, medications, laboratory tests, diagnostic studies, and immunizations. Representative PHRs created with information abstracted from an actual case displayed varying amounts of information at basic and comprehensive levels of representation. CONCLUSIONS: Currently available PHRs demonstrate limited functionality. The data entry, validation, and information display methods they employ may limit their utility as representations of medical information.
SUBJECT HEADINGS: Access to Information\Humans*Internet*Medical Records Systems, Computerized\User-Computer Interface

35. Kimmel Z, Greenes RA, Liederman E. Personal health records. J Med Pract Manage. 2005 Nov-Dec;21(3):147-52. Available from: PMID: 16471387

ABSTRACT: Nationwide, momentum is growing to provide patients with computer tools called personal health records (PHRs). These allow patients to participate in their own healthcare management by viewing, editing, or discussing their own medical data. Historically, PHRs targeted consumers, but contemporary PHRs are increasingly aimed at providers and payers. This article reviews the types of PHRs that are currently available, discusses the PHR functionalities that offer the best value for a medical practice, and provides strategies for making purchasing decisions.
SUBJECT HEADINGS: Ambulatory Care Information Systems\Confidentiality/*legislation & jurisprudence\Humans*Medical Record Linkage\Medical Records/*classification\Medical Records Systems, Computerized\Patient Access to Records/*legislation & jurisprudence*Patient Participation\Practice Management, Medical\United States

36. Klein-Fedyshin MS. Consumer Health Informatics--integrating patients, providers, and professionals online. Med Ref Serv Q. 2002 Fall;21(3):35-50. Available from: PMID: 12238015

ABSTRACT: Consumer Health Informatics (CHI) means different things to patients, health professionals, and health care systems. A broader perspective on this new and rapidly developing field will enable us to understand and better apply its advances. This article provides an overview of CHI discussing its evolution and driving forces, along with advanced applications such as Personal Health Records, Internet transmission of personal health data, clinical e-mail, online pharmacies, and shared decision-making tools. Consumer Health Informatics will become integrated with medical care, electronic medical records, and patient education to impact the whole process and business of health care.
SUBJECT HEADINGS: Access to Information\Computer Communication Networks/*standards\Computer Security\Decision Making\Health Services Accessibility\Humans*Medical Informatics Applications*Medical Records Systems, Computerized\Patient Education/*methods\Patient Participation\Pharmacies\Telecommunications/standards\United States

37. Koonce TY, Giuse DA, Beauregard JM, Giuse NB. Toward a more informed patient: bridging health care information through an interactive communication portal. J Med Libr Assoc. 2007 Jan;95 (1):77-81. Available from: PMID: PMID: 17252070. Available from: http://www.pubmedcentral.nih.gov/articlerender.fcgi?tool=pubmed&pubmedid=17252070

ABSTRACT: The MyHealthatVanderbilt (MHAV) portal encourages patients to become proactive partners in their care management and facilitates open communication with healthcare providers. Interactive features such as appointment scheduling, online bill payment, and secure electronic messaging to providers engage patients in various steps of the healthcare process. Patient data is seamlessly extracted from StarPanel, the Medical Center's electronic health record system, and disclosed to the patient within the MHAV portal. From the beginning of the portal's extensive re-development process in 2005 (which added numerous enhancements), the library has played a key role in the provision of health information and evidence to foster increased patient health literacy. This effort uses several mechanisms: health topics; inclusion of journalist-written news

stories; and patient-oriented information about lab tests.
SUBJECT HEADINGS: Health Education/*organization & administration*Health Knowledge, Attitudes, Practice\Humans\Interdisciplinary Communication\Internet/*organization & administration\Libraries, Digital/*organization & administration\Library Services/*organization & administration\Organizational Objectives*Patient Participation\Program Evaluation\Tennessee\Universities/organization & administration

38. Lober WB, Zierler B, Herbaugh AL, Shinstrom SE, Stolyar A, Kim EH, Kim Y. Barriers to the use of a Personal Health Record by an Elderly Population. AMIA Annu Symp Proc. 2006;514-8. Available from: PMID: 17238394

ABSTRACT: Personal health records (PHRs) are proposed as a strategy to make health care delivery increasingly patient-centered. Yet little work has been done in understanding the workflows of patients in their own homes, or influence of access, cognitive, physical, or literacy barriers on workflow and outcomes of using health records. Many populations may require assistance in using PHRs to improve their health out-comes. We studied PHR use by an elderly and disabled population and describe those barriers encountered by our patients.

39. Lowes R. Personal health records: What's the status now? Med Econ. 2006 Feb 17;83(4):TCP13-4, TCP16. Available from: PMID: 16573223 SUBJECT HEADINGS: Humans*Medical Records\Patient Participation/*utilization\United States

40. McSherry B. Access to confidential medical records by courts and tribunals: the inapplicability of the doctrine of public interest immunity. J Law Med. 2006 Aug;14(1):15-9. Available from: PMID: 16937777

ABSTRACT: A number of Australian courts' decisions have afforded protection to public records. Statutory protection has also been given to counselling records in some jurisdictions in the context of the provision of services to victims of sexual assault. In the aftermath of the extension of public interest immunity in the particular circumstances of Clifford v Victorian Institute of Forensic Mental Health [1999] VSC 359, the argument was raised that a further extension should be made to protect personal health records against attempts at regulatory investigation of allegations of unprofessional conduct. In Royal Women's Hospital v Medical Practitioners Board (Vic) [2006] VSCA 85 the Victorian Court of Appeal unanimously declined to make such an extension. This appears to be indicative of a shift by Australian courts toward compelling disclosure of medical records in the interests of fairness save in very exceptional circumstances.
SUBJECT HEADINGS: Access to Information/*legislation & jurisprudence\Australia\Confidentiality/*legislation & jurisprudence\Female\Forensic Medicine/*legislation & jurisprudence\Hospitals, Public/legislation & jurisprudence\Humans*Liability, Legal\Medical Audit/legislation & jurisprudence\Medical Records/*legislation & jurisprudence\Patient Rights/*legislation & jurisprudence\Specialty Boards/legislation & jurisprudence\Victoria

41. Moen A, Brennan PF. Health@Home: the work of health information management in the household (HIMH): implications for consumer health informatics (CHI) innovations. J Am Med Inform Assoc. 2005 Nov-Dec;12(6):648-56. Available from: PMID: 16049230

ABSTRACT: OBJECTIVE: Contemporary health care places enormous health information management demands on laypeople. Insights into their skills and habits complements current developments in consumer health innovations, including personal health records. Using a five-element human factors model of work, health information management in the household (HIMH) is characterized by the tasks completed by individuals within household organizations, using certain tools and technologies in a given physical environment. DESIGN: We conducted a descriptive-exploratory study of the work of HIMH, involving 49 community-dwelling volunteers from a rural Midwestern community. MEASUREMENTS: During in-person interviews, we collected data using semistructured questionnaires and photographs of artifacts used for HIMH. RESULTS: The work of HIMH is largely the responsibility of a single individual, primarily engaged in the tasks of acquiring, managing, and organizing a diverse set of health information. Paper-based tools are most common, and residents develop strategies for storing information in the household environment aligned with anticipated use. Affiliative relationships, e.g., parent-child or spousal, within the household serve as the organization that gives rise to health information management practices. Synthesis of these findings led to identification of several storage strategies employed in HIMH. These strategies are labeled "just-in-time," "just-because," "just-in-case," and "just-at-hand," reflecting location of the artifacts of health information and anticipated urgency in the need to retrieve it. CONCLUSION: Laypeople develop and employ robust,

complex strategies for managing health information in the home. Capitalizing on these strategies will complement and extend current consumer health innovations to provide functional support to people who face increasing demands to manage personal health information.
SUBJECT HEADINGS: Adolescent\Adult\Aged\Aged, 80 and over\Child\Child, Preschool\Consumer Participation\Female\Humans\Infant\Informatics*Information Management\Interviews\Male*Medical Records\Middle Aged\Midwestern United States*Self Care

42. Mon DT. PHR and EHR: what's the difference? Records differ in span and legality. J AHIMA. 2005 Nov-Dec;76(10):60-1. Available from: PMID: 16333947 SUBJECT HEADINGS: Humans\Medical Records Systems, Computerized/*classification/legislation &\jurisprudence\United States

43. Neame R. Creating an infrastructure for the productive sharing of clinical information. Top Health Inf Manage. 2000 Feb;20(3):85-91. Available from: PMID: 10747439

ABSTRACT: The need for a patient-centered approach to health care services delivery is well recognized. Health care has become more specialized, with increasing numbers of disciplines and subdisciplines. In addition, both providers and community are increasingly mobile. As a consequence, patients see more providers, which has led to increasing fragmentation of patient-centered care and in particular of patients' personal health records. Clinicians and patients alike recognize the need to ensure that care information is patient-centered, continuous, and integrated in order to optimize the effectiveness of proactive and reactive care. Current arrangements, however, including the architecture of medical record and information management systems, are mainly provider- and service-centered and may not readily support the sharing of data to this end.
SUBJECT HEADINGS: *Communication\Great Britain\Humans*Information Services*Interprofessional Relations\Medical Records\Ownership\Patient-Centered Care/*organization & administration\Privacy

44. New-age PHR comes with decision-support, multiple opportunities for DM. Dis Manag Advis. 2006 Dec;12(12):140-2, 133. Available from: PMID: 17225631

ABSTRACT: New-age PHRs aim to uncover opportunities for quality improvement. Health plans have been scrutinizing administrative data for years, but thus far have not offered such analysis to patients or providers. Doing so is just part of the package that will soon be made available to the customers of Manhattan, NY-based ActiveHealth Management through Web-based personal health records. The approach is designed to get patients more involved in their own care, facilitating analysis of not just claims data, but patient-reported data as well.
SUBJECT HEADINGS: *Decision Support Systems, Clinical*Disease Management\Humans*Internet*Medical Records\United States

45. Nobel JJ. Health plan sponsored personal health records: a tool for information driven quality improvement. AHIP Cover. 2005 Nov-Dec;46(6):14-6, 18, 20-5. Available from: PMID: 16450491
SUBJECT HEADINGS: Cost-Benefit Analysis\Humans\Information Management/*organization & administration*Insurance, Health*Medical Records*Quality Assurance, Health Care\United States

46. O'Flaherty S, Jandera E, Llewellyn J, Wall M. Personal health records: an evaluation. Arch Dis Child. 1987 Nov;62 (11):1152-5. Available from: PMID: 3688919

ABSTRACT: A cohort of mothers whose babies were born over one calendar month were followed up eight to 11 months after being given a personal health record for their newborn babies. Eight per cent of mothers lost the records and three more said they had not been given a record while in hospital; a total of 10% of mothers had either lost or misplaced the record. There were no particular demographic characteristics which identified the mothers who were more likely to lose the record. Most parents liked personal health records and used them frequently, as did the community health staff. Most private doctors, however, did not find them useful. Before wider distribution of such records is contemplated health workers should be adequately prepared, especially doctors in the private sector.
SUBJECT HEADINGS: Attitude of Health Personnel*Attitude to Health\Evaluation Studies\Female\Hospitals\Humans\Infant, Newborn*Medical Records\Mothers/*psychology\Postnatal Care/organization & administration\South Australia

47. Recordkeeping systems: personal health records. J Am Med Rec Assoc. 1984 Dec;55(12):42. Available

from: PMID: 10310901 SUBJECT HEADINGS: *Bibliography*Medical Records*Self Care

48. Reinke T. Rise of the PHR. Manag Care. 2007 Jan;16(1):40-2. Available from: PMID: 17285811 SUBJECT HEADINGS: Diffusion of Innovation\Humans\Internet\Medical Records Systems, Computerized/*utilization\United States

49. Report on attitudes about personal health records. Internet Healthc Strateg. 2004 Sep;6(9):10-1. Available from: PMID: 15526437 SUBJECT HEADINGS: Access to Information*Attitude of Health Personnel*Attitude to Computers\Humans*Medical Records Systems, Computerized\Patient Participation\Physicians/psychology\United States

50. Rhoads J, Metzger J. Personal health records: prospects and challenges for health plans. AHIP Cover. 2007 Jan-Feb;48(1):50, 53. Available from: PMID: 17315559 SUBJECT HEADINGS: Humans*Insurance, Health*Medical Records Systems, Computerized\United States

51. Roop L. Technology. Big business charges ahead with personal health records. Hosp Health Netw. 2007 Feb;81(2):17. Available from: PMID: 17373527

52. Sax U, Kohane I, Mandl KD. Wireless technology infrastructures for authentication of patients: PKI that rings. J Am Med Inform Assoc. 2005 May-Jun;12(3):263-8. Available from: PMID: 15684133

ABSTRACT: As the public interest in consumer-driven electronic health care applications rises, so do concerns about the privacy and security of these applications. Achieving a balance between providing the necessary security while promoting user acceptance is a major obstacle in large-scale deployment of applications such as personal health records (PHRs). Robust and reliable forms of authentication are needed for PHRs, as the record will often contain sensitive and protected health information, including the patient's own annotations. Since the health care industry per se is unlikely to succeed at single-handedly developing and deploying a large scale, national authentication infrastructure, it makes sense to leverage existing hardware, software, and networks. This report proposes a new model for authentication of users to health care information applications, leveraging wireless mobile devices. Cell phones are widely distributed, have high user acceptance, and offer advanced security protocols. The authors propose harnessing this technology for the strong authentication of individuals by creating a registration authority and an authentication service, and examine the problems and promise of such a system.
SUBJECT HEADINGS: *Cellular Phone*Computer Security\Confidentiality\Humans\Medical Informatics Applications\Medical Records Systems, Computerized/*standards

53. Shah S, Raman S, Moreira C, MacIntyre CR. School immunisation certificates--a review over time in a disadvantaged community. Aust N Z J Public Health. 2001 Dec;25(6):534-8. Available from: PMID: 11824990

ABSTRACT: OBJECTIVES: To compare proportions of kindergarten children in Auburn presenting School Immunisation Certificates (SIC) or other school-entry immunisation documentation over time, and to examine the immunisation status of these children. METHODS: Immunisation records of kindergarten children enrolled in all primary schools in the Auburn local government area were reviewed in 1994 and 1998. RESULTS: Eight hundred and thirty-three and 737 school entry records of children enrolled in kindergarten were reviewed in 1998 and 1994 respectively. There was no change in the overall proportion of children with immunisation documentation and SICs. Sixty-nine per cent (571/833) of children had SICs in 1998, compared with 72% (531/737) in 1994. Thirteen per cent of children had other immunisation documentation in 1998, compared with 11% in 1994. The proportion of invalid certificates fell from 39.2% in 1994 to 12.6% in 1998 ($p<0.001$). The 1998 survey indicated that 80.2% of children provided a certificate indicating they were completely immunised compared with 56.7% in 1994 ($p<0.001$). IMPLICATIONS: Although SICs play an important role in promoting the importance of immunisation among parents and in the school community, there continues to be a substantial number of children whose immunisation status is unknown. In the event of an outbreak, an effective public health response may need to incorporate the use of

additional objective measures, such as the Australian Childhood Immunisation Register or personal health records.
SUBJECT HEADINGS: Child, Preschool\Cultural Deprivation\Data Collection\Documentation/*standards\Humans\Immunization/*legislation & jurisprudence/*utilization\New South Wales\Records/*standards\Schools/*legislation & jurisprudence\Socioeconomic Factors

54. Sittig DF. Personal health records on the internet: a snapshot of the pioneers at the end of the 20th Century. Int J Med Inform. 2002 Apr; 65(1):1-6. Available from: PMID: 11904243
ABSTRACT: Internet-based, personal health records have the potential to profoundly influence the delivery of health care in the 21st Century, by changing the loci and ownership of the record from one that is distributed among the various health care providers a patient has seen in his lifetime, to one with a single source that is accessible from anywhere in the world and under the shared ownership and control of the patient and his provider(s). Internet-based personal health records (PHRs) include any internet-accessible application that enables a patient (or his guardian, the 'mom') to review, annotate, create or maintain a record of any aspect(s) of his health condition, medication, medical problems, allergies, vaccination history, visit history or communications with his healthcare providers. The current state-of-the-art for personal health records is best characterized as 'beta releases'. As the field matures and gains more experience, these applications will improve significantly in ease of use and functionality.
SUBJECT HEADINGS: Humans*Internet*Medical Records Systems, Computerized

55. Slaughter L, Ruland C, Rotegard AK. Mapping cancer patients' symptoms to UMLS concepts. AMIA Annu Symp Proc. 2005;699-703. Available from: PMID: 16779130
ABSTRACT: A prerequisite for patient-friendly personal health records (PHR) is their ability to allow seamless integration of patient terminology with professional terminologies. In this work, we mapped a set of symptoms/ problems from the self-assessment component of a cancer patient support system to concepts in the Unified Medical Language System (UMLS) Metathesaurus. Our objective was to learn how the UMLS can be used as a tool to connect patient terminology with professional vocabularies. The mapping to UMLS was done with the help of ten expert cancer nurses who evaluated concepts, their synonyms and placement in the source vocabulary hierarchical structure. The UMLS concepts were also compared with terms and phrases found in patient medical records that addressed the same set of symptoms. In this study we observed several problems related to the use of the UMLS Metathesaurus as a tool to connect from patient-level expressions to professional-level classification systems. More work is needed to increase interoperability between layperson health applications and clinical systems.
SUBJECT HEADINGS: Feasibility Studies\Humans*Medical Records\Neoplasms/*complications\Nurses\Patient Care Planning\Patient Participation*Terminology*Unified Medical Language System*Vocabulary

56. Sprague L. Personal health records: the people's choice? NHPF Issue Brief. 2006 Nov 30;(820):1-13. Available from: PMID: 17146910 - http://www.nhpf.org/pdfs_ib/IB820_PHFs_11-30-06.pdf
ABSTRACT: Information technology (IT), especially in the form of an electronic health record (EHR), is touted by many as a key component of meaningful improvement in health care delivery and outcomes. A personal health record (PHR) may be an element of an EHR or a stand-alone record. Proponents of PHRs see them as tools that will improve consumers' ability to manage their care and will also enlist consumers as advocates for widespread health IT adoption. This issue brief explores what a PHR is, the extent of demand for it, issues that need to be resolved before such records can be expected to proliferate, and public-private efforts to promote them.
SUBJECT HEADINGS: Confidentiality\Humans*Medical Records Systems, Computerized*Patient Participation\Patient Rights\Privacy\Security Measures\United States

57. Stead WW. Rethinking electronic health records to better achieve quality and safety goals. Annu Rev Med. 2007;58:35-47. Available from: PMID: 16987082 - http://arjournals.annualreviews.org/doi/abs/10.1146/annurev.med.58.061705.144942
ABSTRACT: Health care information technology changes the ecosystem of a practice. Human roles, process work flow, and technology infrastructure are tightly interrelated. Medical errors may increase if a change in one is not accommodated by a change in the others. Introduction of information technology should be approached as an iterative process of care improvement rather than as a one-time insertion of an information system into

established practice. Information technology supports a family of technological approaches, each with distinct mechanisms of action, benefits, and side effects. By matching technological approach to task and staging introduction into practice, initial benefit can be obtained more quickly, at reduced cost, while managing risk of a misfit. A staged approach to turning direct access by patients to their health information into more effective care is presented as an example of this strategy.

58. 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. Available from: PMID: 16357345 - http://www.jamia.org/cgi/content/full/13/2/121

ABSTRACT: Recently there has been a remarkable upsurge in activity surrounding the adoption of personal health record (PHR) systems for patients and consumers. The biomedical literature does not yet adequately describe the potential capabilities and utility of PHR systems. In addition, the lack of a proven business case for widespread deployment hinders PHR adoption. In a 2005 working symposium, the American Medical Informatics Association's College of Medical Informatics discussed the issues surrounding personal health record systems and developed recommendations for PHR-promoting activities. Personal health record systems are more than just static repositories for patient data; they combine data, knowledge, and software tools, which help patients to become active participants in their own care. When PHRs are integrated with electronic health record systems, they provide greater benefits than would stand-alone systems for consumers. This paper summarizes the College Symposium discussions on PHR systems and provides definitions, system characteristics, technical architectures, benefits, barriers to adoption, and strategies for increasing adoption.
SUBJECT HEADINGS: Attitude to Computers\Attitude to Health*Diffusion of Innovation\Humans*Medical Records*Medical Records Systems, Computerized/utilization\Patient Access to Records\United States

59. Tang PC, Lansky D. The missing link: bridging the patient-provider health information gap. Health Aff (Millwood). 2005 Sep-Oct;24(5):1290-5. Available from: PMID: 16162575

ABSTRACT: Widespread adoption of information technology is now regarded as a pathway to improving health care and achieving the Institute of Medicine's highly regarded six aims for redesigning care. Achieving these aims requires fresh approaches to health system design, including continuous healing relationships between physicians and patients and provision of tools to help patients be more active participants in their own care. Personal health records (PHRs) might allow patients and providers to develop new ways of collaborating and provide the basis for broader transformation of the health care system. Federal policies can be key catalysts in accelerating PHR development and adoption.
SUBJECT HEADINGS: Diffusion of Innovation\History, 21st Century\Humans*Medical Records Systems, Computerized*Physician-Patient Relations\United States

60. Tobacman JK, Kissinger P, Wells M, Prokuski J, Hoyer M, McPherson P, Wheeler J, Kron-Chalupa J, Parsons C, Weller P, Zimmerman B. Implementation of personal health records by case managers in a VAMC general medicine clinic. Patient Educ Couns. 2004 Jul;54(1):27-33. Available from: PMID: 15210257

ABSTRACT: The study objective was to determine the feasibility of implementation of personal health records (PHRs) by case managers (CMs) in a Veterans Affairs Medical Center (VAMC) Continuity of Care (COC) Clinic, to ascertain the impact of PHRs on patient access to vital health information, and to assess the effect on provider-patient communication. One hundred and fifty patients and 8 nurse CMs in the general medicine COC Clinic at the Iowa City VAMC participated in a prospective cohort study in which an intervention, implementation of PHRs, was performed in one half of the patients, selected at random by their CMs. All participants responded to questions about their personal possession of documentation of vital health information. Initially, the majority of subjects possessed poor documentation of basic health information. At follow-up, significant differences occurred between the cohort with PHRs and the cohort without in their documentation of immunizations, allergies, medications, and operations.
SUBJECT HEADINGS: *Access to Information/psychology\Adult\Aged\Aged, 80 and over\Case Management/*standards\Communication\Continuity of Patient Care/standards\Documentation/*standards\Feasibility Studies\Female\Hospitals, Veterans\Humans\Internal Medicine\Iowa\Male\Medical Records/*standards\Middle Aged\Outpatient Clinics, Hospital\Patient Education/standards*Patient Satisfaction\Program Development\Program Evaluation\Prospective Studies\Questionnaires

61. Waegemann CP. Closer to reality. Personal health records represent a step in the right direction for interoperability of healthcare IT systems and accessibility of patient data. Health Manag Technol. 2005 May; 26(5):16, 18. Available from: PMID: 15932068
SUBJECT HEADINGS: Computer Security\Confidentiality\Continuity of Patient Care/*organization & administration\Humans*Internet\Medical Record Linkage*Medical Records Systems, Computerized*Patient Access to Records\Patient Participation\Professional-Patient Relations*Systems Integration\United States

62. Wright A, Sittig DF. Security threat posed by USB-based personal health records. Ann Intern Med. 2007 Feb 20;146(4):314-5. Available from: PMID: 17310061
SUBJECT HEADINGS: *Computer Security\Confidentiality*Medical Records Systems, Computerized\United States

63. Wuerdeman L, Volk L, Pizziferri L, Tsurikova R, Harris C, Feygin R, Epstein M, Meyers K, Wald JS, Lansky D, Bates DW. How accurate is information that patients contribute to their Electronic Health Record? AMIA Annu Symp Proc. 2005;834-8. Available from: PMID: 16779157
ABSTRACT: Increased patient interaction with medical records and the advent of personal health records (PHRs) may increase patients' ability to contribute valid information to their Electronic Medical Record (EHR) medical record. Patient input through a secure connection, whether it be a patient portal or PHR, will integrate many aspects of a patient's health and may help lessen the information gap between patients and providers. Patient reported data should be considered a viable method of enhancing documentation but will not likely be as complete and accurate as more comprehensive data-exchange between providers.
SUBJECT HEADINGS: Ambulatory Care\Data Collection\Depression/diagnosis\Female\Humans\Male*Medical History Taking/standards*Medical Records Systems, Computerized\Mental Recall\Patients