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Personal Health Records: An Annotated Bibliography, Revised

Pam Lane, Deputy Secretary of the California Office of Health Information Integrity, requested that the California Research Bureau (CRB) develop an annotated bibliography to support the department's creation of a strategic plan for providing a personal health record (PHR) to all children in foster care --- part of California's "audacious goal" in the federal health information exchange.

This bibliography is presented in two parts. Part I contains background on PHRs and issues related to implementing an electronic health information system: costs and benefits, sustainability, best practices and patient privacy. Part II contains resources that address PHRs and the special needs of foster children and other vulnerable populations.

Each item includes a summary that has been adapted or quoted from the original material. We conducted a literature search in several databases: EBSCO (Academic Premier and Medline), GoogleScholar, *Health Affairs*, PubMed, and Lexis-Nexis (All News files). We also reviewed the websites of the California Health Care Foundation, the Markle Foundation and the UCLA Center for Health Policy Research. In our searches, we used the terms "electronic medical record," "electronic health record," "health information exchange," "electronic care record," "personal health record" and "health passport."

We have included links to sources for which the full text are freely available. For items without links, please contact The Children's Partnership (Ginny Puddefoot at gpuddefoot@childrenspartnership.org).

Glossary of Terms:

CHP: Child Health Providers
DoD: Department of Defense
ECR: Electronic Care Record
EHR: Electronic Health Record
EMR: Electronic Medical Records
EPR: Electronic Patient Record
HIE: Health Information Exchange
HIMSS: Health Information Management Systems Society
HIPAA: Health Insurance Portability and Accountability Act
HIT: Health Information Technology
ID: Identification
IT: Information Technology
MHV: MyHealtheVet
NwHIN: Nationwide Health Information Network
PHR: Personal Health Record
VA: U.S. Department of Veterans Affairs
VHA: U.S. Veteran's Health Administration

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Part I: Background and Issues:

General Background:

Archer, Norm, et al., "Personal Health Records: A Scoping Review," ***Journal of the American Medical Informatics Association*** **18, no. 4 (July-August 2011): 515-522.**

> Summary: This scoping review on PHR includes design, functionality, implementation, applications, outcomes, and benefits. One of the main findings in this review is that PHRs are likely to be linked to physician EMR systems, so PHR adoption is dependent on growth in EMR adoption. Many PHR systems are physician-oriented, and do not include patient-oriented functionalities. These must be provided to support self-management and disease prevention if improvements in health outcomes are to be expected. Differences in patient motivation to use PHRs exist, but an overall low adoption rate is to be expected, except for the disabled, chronically ill, or caregivers for the elderly. Finally, trials of PHR effectiveness and sustainability for patient self-management are needed.

Bassinder, James, et al., "Knowledge Management and Electronic Care Records: Incorporating Social, Legal and Ethical Issues," ***Studies in Health Technologies and Informatics*** **121 (2006): 221-227.**

> Summary: A sound knowledge management (KM) structure within clinical environments can recognize the responsibility of healthcare professionals to keep patient clinical data (for example, ECR systems) secure. An arrangement is proposed that gives the most senior clinician in a healthcare facility the ultimate responsibility for security of clinical data held in the organization. Ideally, the senior clinician would possess training and experience in information systems and their security. Contracts should be developed between healthcare facilities and their patients, defining the limits to the use and disclosure of clinical health data. However, we are observing increasing confusion about the term 'knowledge management,' which may be limited both its efficacy and effectiveness. Health organizations are referring to the term in various contexts and health informatics articles frequently use the term and interpret it in diverse ways. Given the divergence of views, this paper will attempt to establish KM's efficacy for the implementation of ECR systems.

Uslu, Aykut M., et al., "Value of the Electronic Patient Record: An Analysis of the Literature," ***Journal of Biomedical Informatics*** **41 (2008): 675-682.**

> Summary: Researchers undertook a systematic review of the literature on the basis of published studies on the benefit and costs of EPRs to clarify the issue of whether and to what extent the use of an EPR is worthwhile. They carried out a systematic electronic search for articles published between 1966 and early 2004 using MEDLINE, following up cross-references from the articles found. The publications evaluated thus document the economic benefits of EPR in a number of areas, but they do not make a statement of the cost effectiveness of EPR in general.

Weitzman, Elissa R., et al., "Sharing Medical Data for Health Research: The Early Personal Health Record Experience," ***Journal of Medical Internet Research*** **12, no. 2 (2010): e14.**
http://www.jmir.org/2010/2/e14/

> Summary: The objective of this study was to characterize consumer willingness to share personally controlled health records (PCHR) data for health research and the conditions and contexts bearing on willingness to share. Select differences in support for sharing under different conditions were observed across social groups. No gender differences were observed; however, differences in age, role, and self-rated health were found. For example, students were more likely than nonstudents to favor an opt-out sharing default. Experiencing a public health emergency may increase their willingness to share especially among persons over 50. However, students were less likely than non-students to report this attitude. Finally, subjects with fair or poor self-rated health were less likely than those with good to excellent self-rated health to report that willingness to share would increase during a public health emergency. Strong support for sharing of PCHR information for health research existed among early adopters and focus group participants, with support varying by social group under different conditions and contexts. Allowing users to select their preferred conditions for sharing may be vital to supporting sharing and fostering trust as may be development of safety monitoring mechanisms.

Wynia, Matthew K., et al., "Many Physicians Are Willing to Use Patients' Electronic Personal Health Records, but Doctors Differ by Location, Gender and Practice," ***Health Affairs*** **30, no. 2 (February 2011): 266-273.**

> Summary: With the emergence of new products and federal incentives that might indirectly encourage greater use of personal health records, policy makers should understand the views of physicians on using these records. In a national survey of physicians in 2008–09, researchers found that 64% of their respondents had never used a patient's electronic personal health record, but 42% of them would be willing to try. Strikingly, rural physicians expressed much more willingness to use such records compared to urban or suburban physicians. Female physicians were significantly less willing to use these tools than their male peers (34% versus 46%). Physicians broadly have concerns about the impact on patients' privacy, the accuracy of underlying data, their potential liability for tracking all of the information that might be entered into a personal health record, and the lack of payment to clinicians for using or reviewing these patient records.

Wulsin, Lucien, et al., ***Health Information Technology – Electronic Health Records: A Primer*****. California Research Bureau (September 2008): 1-27.**
http://www.library.ca.gov/crb/08/08-013.pdf

> Summary: Health Information Technology-Electronic Health Records (HIT-EHR) is a broad term that refers to the generation, storage, and transmission of electronic health information. This report highlights recent developments and explains various aspects of

HIT-EHR, including definitions, current usage, how it can benefit healthcare quality and costs, barriers to its development, and current public and private efforts to implement and expand it.

Best Practices/Implementation:

Bouhaddou, Omar, et al., "The Department of Veterans Affairs, Department of Defense, and Kaiser Permanente Nationwide Health Information Network Exchange in San Diego: Patient Selection, Consent, and Identity Matching," In *American Medical Informatics Association Annual Symposium Proceedings* 2011: 135-143.
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3243253/

Summary: The NwHIN allows for the secure exchange of EHRs over the Internet. The VA, DoD and Kaiser Permanente, participated in an implementation of the NwHIN specifications in San Diego, California. This paper focuses primarily on patient involvement. Specifically, it describes how the shared patients were identified, were invited to participate and to provide consent for disclosing parts of their medical record, and were matched across organizations. A total of 1,144 were identified as shared patients. Invitation letters containing consent forms were mailed and resulted in 42% participation. Invalid consent forms were a significant issue (25%). Initially, the identity matching algorithms yielded low success rate (5%). However, elimination of certain traits and abbreviations and probabilistic algorithms have significantly increased the matching rate. Access to information from external sources better informs providers, improves decisions and efficiency, and helps meet the meaningful-use criteria.

Gill, Jasdeep, et al., "Presenting Patient Data in the Electronic Care Record: The Role of Timelines," *Journal of the Royal Society of Medicine – Short Reports* 1, no. 4 (September 2010): 29.
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2984360/

Summary: The purpose of this study was to establish the current level of awareness and investigate the use of timelines within clinical computing systems as an organized display of the EPR. Seven hospitals and general practice surgeries in the United Kingdom completed a questionnaire regarding their use of clinical timelines. Fifty-eight percent of participants had not heard of the specific term 'timelines' despite 75% of users utilizing a form of timeline on a daily basis. The potential benefits of future timelines were clinical audit, increased time efficiency, reduced clinical error, and improved patient safety. One continuous timeline view between primary and secondary care was considered to be of great potential benefit in allowing communication via a unified patient record.

Gordon, Jeffrey, "Educating the Patient: Challenges and Opportunities with Current Technology," *The Nursing Clinics of North America* 46, no. 3 (September 2011): 341-350.

Summary: The patient portal and the PHR will become the dominant way that patients interact with their own clinical data. The portal allows patients to view their own data, and the PHR allows them to collect, enter and store their own data. Patients can develop portfolios by adding information found on the Internet, or submitting photos or other supporting documents to their record. With e-mail, videoconferencing, etc. available, health care providers will be involved in a more interactive education process with their patients than they have been traditionally.

Health Information and Management Systems Society, Health Information Exchange Best Practices Task Force, *Health Information Exchanges: Similarities and Differences*, HIMSS HIE Common Practices Survey Results White Paper, March 2009: 1-39.
http://tinyurl.com/cxtn3az

Summary: This study sought to understand HIE entities better through a survey regarding organizational formation, structure and technical components. Several trends were observed based on the responses to the survey from the participating HIEs: 60% of the organizations surveyed depended on grants for long-term sustainability, 70% chose to buy an HIE system rather than build their own, and 85% looked at interoperability with other federal and state HIE systems as a concern for their own system.

Kahn, James, et al., "What It Takes: Characteristics of the Ideal Personal Health Record" *Health Affairs* 28, no. 2 (March/April 2009): 369-376.
http://content.healthaffairs.org/content/28/2/369.full.pdf+html

Summary: There is a gap between today's PHRs and what patients say they want and need from this electronic tool for managing their health information. Until that gap is bridged, it is unlikely that PHRs will be widely adopted. Current barriers to PHR adoption among patients include: cost, concerns that information is not protected or private, inconvenience, design shortcomings, and the inability to share information across organizations. However, in the future, when these concerns are addressed, and health data are portable and understandable (in both content and format), PHRs will likely prove to be invaluable.

Kellerman, Arthur T., et al., "What It Will Take To Achieve The As-Yet-Unfulfilled Promises of Health Information Technology?" *Health Affairs* 32, no.1 (2013): 63-68.

Summary: The disappointing performance of HIT to date can be largely attributed to several factors: sluggish adoption of HIT systems, coupled with the choice of systems that are neither interoperable nor easy to use; and the failure of health care providers and institutions to re-engineer care processes to reap the full benefits of HIT. The original promise of HIT can be met if the systems are redesigned to address these flaws by creating more-standardized systems that are easier to use, are truly interoperable, and afford patients more access to and control over their health data.

Krist, Alex, et al., "Designing a Patient-Centered Personal Health Record to Promote Preventive Care," ***BMC Medical Informatics and Decision Making*** **11, no. 73 (2011): 1-11.**
http://www.biomedcentral.com/1472-6947/11/73

> Summary: Using a previously described model to make IT more patient-centered, researchers developed an interactive preventive health record (IPHR) designed to more deeply engage patients in preventive care and health promotion. The input involved patient usability tests, practice workflow observations, learning collaboratives, and patient feedback. Use of the IPHR was measured using practice appointment and IPHR databases. The IPHR that emerged from this process generated tailored patient recommendations based on guidelines from the U.S. Preventive Services Task Force and other organizations. The IPHR demonstrated that a patient-centered personal health record that interfaces with the EMR can give patients a high level of individualized guidance and be successfully adopted by busy primary care practices. Further study and refinement are necessary to make information systems even more patient-centered and to demonstrate their impact on care.

Markle Connecting for Health Collaborators, ***The Markle Connecting for Health Common Framework Policies in Practice for Health Information Sharing: Overview,*** **April 2012: 1-9.**
http://www.markle.org/sites/default/files/Overview%20Final.pdf

> Summary: The *Policies in Practice* were developed through a collaborative process by a diverse group of health care leaders with hands-on experience implementing health information sharing efforts, including state health IT leaders, legal experts, technology experts, and consumer representatives. This compendium of practices further specifies the Markle Common Framework to address a range of critical implementation needs for health information sharing in today's rapidly changing environment. These *Policies in Practice* address the following areas: key laws and regulations, patient consent, individual access to health information, governance of HIE efforts, technology procurement strategies, and system oversight and accountability.

Markle Connecting for Health Collaborators, ***The Markle Connecting for Health Common Framework Policies in Practice for Health Information Sharing: Governance of Health Information Sharing Efforts: Achieving Trust and Interoperability With Meaningful Consumer Participation*****, April 2012: 1- 23.**
http://www.markle.org/sites/default/files/Governance%20softlaunch.pdf

> Summary: This resource describes how health information sharing efforts can achieve trust and interoperability through sound governance principles and mechanisms, and provides real-world examples that illustrate how these principles can be manifest in practice.

Markle Connecting for Health Work Group on Consumer Access Policies for Networked Personal Health Information, *Common Framework for Networked Personal Health Information: Overview and Principles*, June 2008: 1-209.
http://www.markle.org/sites/default/files/CF-Consumers-Full.pdf

> Summary: This framework provides a foundation for maintaining trust among all participants — business, professional, and consumer — in electronic health information networks. The objective is to give consumers the ability to compile electronic copies of their personal health information, including their own contributions, under a set of fair practices that respect personal preferences for how information may be collected and shared. The term "networked" implies connectivity across entities. Networking health information is critical given the fragmentation of most health-related services in the United States.

Miller, Robert H., "Satisfying Patient-Consumer Principles for Health Information Exchange: Evidence From California Case Studies," *Health Affairs* 31, no. 3 (March 2012): 537-547.

> Summary: This study assesses to what extent five health care organizations --- all in different stages of increasing their capacity for HIE — conformed to principles established in June 2010 for electronically exchanging health information among providers. Although an increasing amount of electronic data has been exchanged among organizations and with patients, progress has been modest, and patients still have little control over their data. For organizations to comply with all nine patient and consumer principles, clear "rules of the road" for information sharing must be defined, and patient education in HIE and control over personal data must be increased.

Mills, Mary E., et al. 2009. Creating a Governmental Policy Framework for Adoption of an Electronic Health Record. *Studies in Health Technology and Informatics* 146: 678-82.

> Summary: Promotion and support of electronic health records and electronic information exchange through governmental policy development requires a framework that considers cost, benefits, barriers, risks and policies at the statewide level that might accelerate or retard adoption. Recommendations to underpin governmental policy involve financial incentives, technology adoption, legal and regulatory considerations and consumer education.

Pourat, Nadereh, et al., *Achieving System Integration in California's Healthcare Safety Net*, Health Economics and Evaluation Research Program, UCLA Center for Health Policy Research (August 2012): 1-67.
http://healthpolicy.ucla.edu/publications/Documents/PDF/HCCIreport-aug2012.pdf

> Summary: Ten California counties established a patient-centered health care system that provides access to coordinated and efficient care. These counties have effectively transitioned from a fragmented safety-net model to an integrated health care network as part of the State of California's Health Care Coverage Initiative. The findings describe

county advances in improving specialty access, quality of care, and health information technology.

Reti, Shane, et al., "Improving Personal Health Records for Patient-Centered Care," ***Journal of the American Medical Informatics Association*** **17, no. 192 (2010): 192-195.**

Summary: The purpose of this study was to assess the patient-centeredness of PHRs and offer recommendations for best practice guidelines. Patient-centeredness was assessed against a framework of care that includes: (1) respect for patient values, preferences, and expressed needs; (2) information and education; (3) access to care; (4) emotional support to relieve fear and anxiety; (5) involvement of family and friends; (6) continuity and secure transition between healthcare providers; (7) physical comfort; and, (8) coordination of care. Within this framework, researchers used evidence for patient preferences (where it exists) to compare existing PHR policies, and proposed a best practice model. Researchers found that most organizations enable many patient-centered functions such as data access for proxies and minors. No organization allows patient views of clinical progress notes, and turnaround times for PHR reporting of normal laboratory results can be up to 7 days. Findings suggest patient-centeredness for personal health records can be improved, and recommendations are made for best practice guidelines.

Shields, Alexandra E., et al., "Adoption of Health Information Technology in Community Health Centers: Results of a National Survey," ***Health Affairs*** **26, no. 5 (September 2007): 1373-1383.**
http://content.healthaffairs.org/content/26/5/1373.full.pdf+html

Summary: This first national survey of federally funded community health centers (CHCs) shows that although 26% reported some EHR capacity and 13% have the minimal set of EHR functionalities, CHCs serving the most poor and uninsured patients were less likely to have a functional EHR. CHCs cited lack of capital as the top barrier to adoption. Ensuring comparable health IT capacity among providers that disproportionately serve disadvantaged patients will have increasing relevance for disparities. Thus, monitoring adoption among such providers should be a priority.

Walker, James M., et al., "From Tasks To Processes: The Case For Changing Health Information Technology To Improve Health Care," ***Health Affairs*** **28, no. 2 (March/April 2009): 467-477.**

Summary: To deliver better health care at a lower cost, HIT should be redesigned to support improved, patient-centered care and not the isolated tasks of physicians and clinicians. This new approach has major policy implications: HIT can help mitigate the worsening shortages of physicians; it will require managers, clinicians, and patients to learn new skills and behaviors; it will increase the need for clinically astute systems analysts, business-process managers, and human-factors engineers; and it will highlight the need to pay for process improvements and improved patient well-being rather than the mere purchase of HIT.

__Costs and Benefits/Sustainability__:

Anderson, Gerard F., et al., "Health Care Spending and Use of Information Technology in OECD Countries," *Health Affairs* 25, no. 3 (May 2006): 819-831.
http://content.healthaffairs.org/content/25/3/819.full.pdf+html

> __Summary__: In 2003, the United States had fewer practicing physicians, practicing nurses, and acute care bed days per capita than the median country in the Organization for Economic Cooperation and Development (OECD). Nevertheless, U.S. health spending per capita was almost two and a half times the per capita health spending of the median OECD country. One proposal for both lowering health spending and improving quality is the adoption of HIT. The United States lags as much as a dozen years behind other industrialized countries in HIT adoption—countries where national governments have played major roles in establishing the rule, and health insurers have paid most of the costs.

Bostick, Renee M., et al., *Sustaining State Health Information Exchange: A State Toolkit*, A Report Commissioned by the National Governor's Association Center for Best Practices State Alliance E-Health, Health Management Associates, Inc., March 2011: 1-46.
http://www.nga.org/files/live/sites/NGA/files/pdf/1103SUSTAININGHIETOOLKIT.PDF

> __Summary__: This toolkit addresses how health information organizations can create and deliver value to achieve long-term sustainability in HIE systems. Sustainability remains the top issue of concern as states continue to develop their HIE capabilities. Leading health information organizations have found success with emphasis on participatory governance, implanting services that customers support, and the idea that incremental progress builds momentum for long-term reforms.

Buntin, Melinda B., et al., "The Benefits Of Health Information Technology: A Review of the Recent Literature Shows Predominantly Positive Results," *Health Affairs* 30, no. 3 (March 2011): 464-471.
http://content.healthaffairs.org/content/30/3/464.full.pdf+html

> __Summary__: Researchers reviewed the recent literature on health information technology to determine its effect on outcomes, including quality, efficiency, and provider satisfaction. They found that 92% of the recent articles on health information technology reached conclusions that were positive overall. They also found that the benefits of the technology are beginning to emerge in smaller practices and organizations, as well as in large organizations that were early adopters. However, dissatisfaction with electronic health records among some providers remains a problem and a barrier to achieving the potential of health information technology. These realities highlight the need for studies that document the challenging aspects of implementing health information technology more specifically and how these challenges might be addressed.

Campbell, Robert N., et al., *(HIE) Business Models: The Path to Sustainable Financial Success*, Deloitte Center for Health Solutions, 2006: 1-12.
http://tinyurl.com/c8zagsr

> Summary: This paper explores current and emerging HIE business models, reviews the elements of successful models, and examines current and future challenges as they relate to HIEs and sustainability.

Carr, Kevin, et al., "Leveraging the Benefits of Health Information Technology to Support Healthcare Delivery Model Redesign," *Journal of Healthcare Information Management* 20, no. 1 (Winter 2006): 31-41.

> Summary: Uninsured and low income underinsured patients create substantial challenges for local healthcare systems, yet their providers are not always included in community-wide implementations of health information technology. In 2003, a consortium of providers founded the Waterbury Health Access Program (WHAP) to implement an EMR system that would first address the needs of the region's vulnerable underserved patients. It was anticipated that lessons learned would be applicable to other patient populations as well. The WHAP consortium of competing hospitals and outpatient clinics developed a broad-based community-wide initiative to include implementing a common EMR system to share clinical information across all locations. The design included 11 outpatient clinic locations linked to a common data-sharing tool that is accessible by each clinic, emergency department and community practitioner participating in a local, coordinated charity care program. The collaboration required to support community-wide implementations of health information technology also can be leveraged to facilitate additional quality improvement initiatives.

Dimmitt, Michael, *Healthcare Reform: Selected Topics Seminars*, California Research Bureau (February 2010): 1-32.
http://www.library.ca.gov/crb/10/10-001.pdf

> Summary: This report is a synthesis of the materials from seminars on healthcare reform. The backdrop for these seminars was healthcare cost containment. The initial seminar's purpose was to address what many scholars and professionals regard as a key ingredient of cost control, Health Information Technology-Electronic Medical Record (HIT-EMR). Some scholars have estimated that a broad-based focus of HIT-EMR could produce substantial cost savings. Others believe the savings from the widespread adoption of HIT would be nominal, so the adoption of HIT-EMR should be directed to the significant quality deficit in the health system. Both paths have significant consequences as they relate to the goals of universal healthcare coverage.

Goldzweig, Caroline L., et al., "Costs and Benefits of Health Information Technology: New Trends from the Literature," *Health Affairs* 28, no. 2 (March/April 2009): w282-w293.
http://content.healthaffairs.org/content/28/2/w282.full.pdf+html

> Summary: To understand what is new in HIT, the researchers updated a systematic review of HIT with studies published during 2004–2007. They identified a proliferation of patient-focused applications and descriptions of commercial EHRs and HIT systems designed to run independently from EHRs; and proportionately fewer relevant studies from the HIT leaders. Accelerating the adoption of HIT will require greater public-private partnerships, new policies to address the misalignment of financial incentives, and a more robust evidence base regarding IT implementation.

Grant, Chad, *Sustainable Success: State CIOs and Health Information Exchange*, National Association of State Chief Information Officers, September 2011: 1-10
http://www.nascio.org/publications/documents/NASCIO_HIESustainabilityBrief_September2011.pdf

> Summary: This issue brief highlights the importance of sustainable public HIE systems, and possible revenue streams that can create longevity. State CIOs and state policy officials need to consider the business drivers that will ensure that revenues exceed costs to plan, implement and operate an interoperable HIE. Splitting the costs of an HIE system among stakeholders, establishing subscription fees and seeking out private funding sources are strong recommendations.

Privacy:

Carrión, Immaculada, et al., "Are Personal Health Records Safe? A Review of Free Web-Accessible Personal Health Record Privacy Policies," *Journal of Medical Internet Research* 23, no. 14 (August 2012): e114-e123.
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3510685/

> Summary: It is hoped that identification of the strengths and weaknesses of the PHR systems will be useful for PHR users, health care professionals, decision makers, and designers. Researchers conducted a systematic review using the principal databases related to health and computer science to discover the Web-based and free PHR systems mentioned in published articles. The privacy policy of each PHR system selected was reviewed to extract its main privacy and security characteristics. In a review of 24 PHR systems, 71% allowed users to manage their data and to control access to their health care information. Only 38% of the PHR systems permitted users to check who had accessed their data. The majority of PHR systems used information related to the users' accesses to monitor and analyze system use, 50% of them aggregated user information to publish trends, and 83% used diverse types of security measures. Finally, 63% of the PHR systems were based on regulations or principles such as HIPAA and the Health on the Net Foundation Code of Conduct. Most privacy policies of PHR systems do not provide

an in-depth description of the security measures that they use. Moreover, compliance with standards and regulations in PHR systems is still low.

Carrión, Immaculada. 2011. Assessing the HIPAA Standard in Practice: PHR Privacy Policies. In 33rd *Annual International Conference of the IEEE Engineering in Medicine and Biology Society*: 2380-2383.
https://www2.lirmm.fr/lirmm/interne/BIBLI/CDROM/ROB/2011/EMB_2011/PDFs/Papers/06272734.pdf

Summary: Health service providers are starting to become interested in providing PHRs (personal health records). With PHRs, access to data is controlled by the patient, and not by the health care provider. Companies such as Google and Microsoft are establishing a leadership position in this emerging market. A number of benefits can be achieved with PHRs, but important challenges related to security and privacy must be addressed. This paper presents a review of the privacy policies of 20 free web-based PHRs. Security and privacy characteristics were extracted and assessed according to the HIPAA standard. The results show a number of important differences in the characteristics analyzed. Some improvements can be made to current PHR privacy policies to enhance the audit and management of access to users' PHRs. A questionnaire has been defined to assist PHR designers in this task.

Frost, Jeana H., et al., "Social Uses of Personal Health Information Within PatientsLikeMe, An Online Patient Community: What Can Happen When Patients Have Access To One Another's Data," ***Journal of Medical Internet Research*** **27, no. 10 (May 2008): e15.**
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2553248/

Summary: PatientsLikeMe is an online community built to support information exchange between patients. The site provides customized disease-specific outcome and visualization tools to help patients understand and share information about their condition. Few studies examine the use of personal health information by patients themselves. This project suggests how patients who choose to explicitly share health data within a community may benefit from the process, helping them engage in dialogues that may inform disease self-management. We recommend that future designs make each patient's health information as clear as possible, automate matching of people with similar conditions and using similar treatments, and integrate data into online platforms for health conversations.

Markle Connecting For Health Collaborators, ***The Markle Connecting for Health Common Framework for Private and Secure Health Information Exchange: Overview and Principles*****, 2006: 1-448.**
http://www.markle.org/sites/default/files/CF-Professionals-Full.pdf

Summary: This framework puts forth a model of health information exchange that protects patient privacy by allowing health information to remain under local control, with the doctors and hospitals patients trust, thus avoiding the need for large, centralized databases or creation of a national patient identification system. It also avoids large scale disruption and huge up front capital investments by making use of existing hardware and software. This flexibility enables innovation and the ability to customize solutions to meet local needs. Finally, this framework supports better informed decisions about key policy topics related to sharing health information and establishes trust among collaborating organizations by applying well-vetted model contract language, in consultation with local advisors, to fit their needs.

Markle Connecting for Health Collaborators, *The Markle Connecting for Health Common Framework Policies in Practice for Health Information Sharing: Consent: Implementing the Individual Participation and Control Principle in Health Information Sharing,* April 2012: 1-20.
http://www.markle.org/sites/default/files/Consent%20Final.pdf

Summary: This document provides implementation context for the Individual Participation and Control principle of the Markle Common Framework and suggests ways for health information sharing efforts to establish their own policies and best practices on this issue, including a sequence to inform consideration of consent policies.

Markle Connecting for Health Collaborators, *The Markle Connecting for Health Common Framework Policies in Practice for Health Information Sharing: Individual Access: Connecting Patients with Their Health Information*, April 2012: 1-16.
http://www.markle.org/sites/default/files/Individual%20Access%20Final.pdf

Summary: This document outlines the basic requirements for giving patients access to personal health information through a download capability. It draws upon consensus-based recommendations reflected in the Markle Common Framework.

Markle Connecting for Health Collaborators, *The Markle Connecting for Health Common Framework Policies in Practice for Health Information Sharing: Key Laws and Regulations: Changes Relevant to the Markle Common Framework*, April 2012: 1-23.
http://www.markle.org/sites/default/files/Key%20Laws%20and%20Regulations%20Final.pdf

Summary: This publication updates relevant information on HIPAA privacy and security laws addressed throughout the Markle Common Framework. It summarizes a survey of important federal, legal and regulatory changes, since release of the Markle Common Framework through January 2012, that affect the exchange of individually identifiable health care information.

Markle Connecting for Health Collaborators, *The Markle Connecting for Health Common Framework Policies in Practice for Health Information Sharing: Policy-Aware Procurement Strategies and Practices: Asking the Right Questions & Reaching the Right Answers*, April 2012: 1-21.
http://www.markle.org/sites/default/files/Getting%20Procurement%20Right%20Final.pdf

> Summary: This document describes how health information sharing efforts can use their privacy and security policies and procedures to guide their dialogue with prospective technology developers toward the procurement and implementation of health information products and/or services that support policy objectives.

Moore, Ros, "Examining the Impact Of Electronic Care Records on Confidentiality and Nursing Practice," *Nursing Times* 106, no. 14 (April 2010): 16-18.
http://tinyurl.com/chjg96g

> Summary: ECRs have significant implications both for frontline nurses and the wider profession. This article examines the issues nurses must consider when introducing and using an ECR system. These issues include access and information governance, and matters such as confidentiality.

U.S. Government Accountability Office, *HHS Has Taken Important Steps to Address Privacy Principles and Challenges, Although More Work Remains,* September 2008: 1-27.
http://www.gao.gov/assets/290/281089.pdf

> Summary: In 2007, the U.S. Government Accountability Office (GAO) made recommendations to the HHS on how to ensure the protection of personal health information exchanged in a national network, including: (1) identifying milestones and the entity responsible for integrating the outcomes of its privacy-related initiatives, (2) ensuring that key privacy principles in HIPAA are fully addressed, and (3) addressing key challenges associated with the nationwide exchange of health information. This 2008 report found that the department had fulfilled the first part of its recommendations, and had taken important steps in addressing the two other parts. However, these steps had fallen short of fully implementing GAO's recommendations because they did not include a process for ensuring that all key privacy principles and challenges will be fully and adequately addressed. In the absence of such a process, HHS may not be effectively positioned to ensure that health IT initiatives achieve comprehensive privacy protection within a nationwide health information network.

Part II: Children, Foster Youth and Other Vulnerable Populations

Children/Young Adults:

Brinner, Kristin A., et al., "Advancing Patient-Centered Pediatric Care through Health Information Exchange: Update from the American Health Information Community Personalized Health Care Workgroup," ***Pediatrics*** **123, Supplement no. 2 (January 2009): S122-S124.**
http://pediatrics.aappublications.org/content/123/Supplement_2/S122.full.pdf+html

> Summary: The Personalized Health Care Workgroup developed a series of use cases that outlined the informational needs of multiple stakeholders (e.g., patients, clinicians, organizations, and systems) and described the information systems necessary to connect these stakeholders at multiple levels. These case scenarios offer a guide for standardized data elements and architecture that enable interoperability (content sharing) among different formats of patient electronic health records.

Britto, Maria T., et al., "Pediatric Personal Health Records: Current Trends and Key Challenges," ***Pediatrics*** **123, Supplement no. 2 (January 2009): S97-S99.**
http://pediatrics.aappublications.org/content/123/Supplement_2/S97.full.pdf+html

> Summary: Personal health records may enhance pediatric care and outcomes. Few systems have been developed or customized for pediatrics, and evaluations are scarce. Special considerations in pediatrics include pediatric content such as growth charts, complex privacy and confidentiality considerations, and the changing developmental needs of children and adolescents.

Co, Patrick T., et al., "Electronic Health Record Decision Support and Quality of Care for Children with ADHD," ***Pediatrics*** **126, no. 2 (August 2010): 239-246.**
http://pediatrics.aappublications.org/content/126/2/239.full.pdf

> Summary: The objective of this study was to assess the effect of EHR decision support on physician management and documentation of care for children with attention-deficit/hyperactivity disorder (ADHD). Researchers conducted a cluster randomized trial of EHR-based decision support that included (1) clinician reminders to assess ADHD symptoms every 3 to 6 months and (2) an ADHD note template with structured fields for symptoms, treatment effectiveness, and adverse effects. The main outcome measures were (1) proportion of children with visits during the 6-month study period in which ADHD was assessed and (2) quality of documentation of ADHD assessment. The ADHD template was used at 32% of visits at which patients were scheduled specifically for ADHD assessment, and its use was associated with improved documentation of symptoms, treatment effectiveness, and treatment adverse effects. EHR-based decision support improved the likelihood that children with ADHD had visits for care related to managing this condition. Better understanding of how to optimize provider use of the decision support and templates could promote additional improvements in care.

Conway, Patrick H., et al., "The Public Role in Promoting Child Health Information Technology," *Pediatrics* 123, Supplement no. 2 (January 2009): S125-S127.
http://pediatrics.aappublications.org/content/123/Supplement_2/S125.full.pdf

> Summary: Public sector support is essential in 5 main aspects of child health information technology, namely, data standards, pediatric functions in health information systems, privacy policies, research and implementation funding, and incentives for technology adoption. Some innovations in health information technology for adult populations can be transferred to or adapted for children, but there also are unique needs in the pediatric population. Development of health information technology that addresses children's needs and effective adoption of that technology are critical for U.S. children to receive care of the highest possible quality in the future.

Council on Clinical Information Technology, "Policy Statement ---- Using Personal Health Records to Improve the Quality of Health Care for Children," *Pediatrics* 124, no. 1 (July 2009): 403-409.
http://pediatrics.aappublications.org/content/124/1/403.full.pdf

> Summary: The development of electronic PHRs presents new opportunities and challenges to the practice of pediatrics. This policy statement provides recommendations for actions that pediatricians can take to support the development and use of PHRs for children. The American Academy of Pediatrics supports development of: educational programs for families and clinicians on effective and efficient use of PHRs; incentives to facilitate PHR use and maintenance; and child- and adolescent-friendly standards for PHR content, portability, security, and privacy. For PHRs to be adopted sufficiently to realize these benefits, we must determine how best to support their development and adoption. Privacy and security issues, especially with regard to children and adolescents, must be addressed.

Fairbrother, Gerry, et al., "It Is Time! Accelerating the Use of Child Health Information Systems to Improve Child Health," *Pediatrics* 123, Supplement no. 2 (January 2009): S61-S63.
http://pediatrics.aappublications.org/content/123/Supplement_2/S61.full.pdf

> Summary: This article provides an overview of the studies in this special supplement of *Pediatrics*, addressing the issues and challenges of creating health information systems for children. The research contained in this issue shows the enormous impact that the use of health information technology can have on the quality of health care for children. However, the authors also point to challenges such as interoperability, infrastructure and funding that need to be overcome to realize fully the potential of health information technology to improve the quality and efficiency of health care.

Hagan, Joseph F., "Discerning the Bright Future of Electronic Records," ***Pediatric Annals*** **37, no. 3 (March 2008): 173-179.**
http://tinyurl.com/blauqfe

> Summary: This article discusses the release of the Bright Futures Guidelines, third edition, by the American Academy of Pediatrics. The document provides guidelines on conducting patient visits: necessary screenings/tests, and anticipatory guidance. Pediatricians, with their colleague nurse practitioners and family physicians, now address "new morbidities" of behavioral and psychosocial problems, developmental disabilities, and environmental stressors, in addition to the traditional morbidities of infection or malnutrition. Properly designed EHRs (electronic healthcare records) can add efficiency to this important work. The author suggests that the Bright Futures Guidelines be implemented in an EHR system.

Haney, Tina, et al., "A Pilot Study Using Electronic Communication in Home Healthcare: Implications on Parental Well-Being and Satisfaction Caring for Medically Fragile Children," ***Home Healthcare Nurse*** **30, no. 4 (April 2012): 216-224.**

> Summary: The aim of this study was to explore the impact of a nurse-established and nurse-managed electronic communication in the form of e-mail on the self-reported well-being and satisfaction of parents caring for medically fragile and technologically dependent children. This study was conducted in a pediatric home care agency located in the southeastern region of the United States. There were no significant differences in pre- and post-intervention parental self-reported well-being or satisfaction. Parental qualitative comments suggest positive outcomes related to well-being and satisfaction. Further investigation into the utility of e-mail communication with parents of medically fragile and technologically dependent children cared for at home is warranted.

Hinman, Alan R., et al., "Integrating Child Health Information Systems," ***American Journal of Public Health*** **95, No. 11 (November 2005): 1923-1927.**
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1449460/

> Summary: The Health Resources and Services Administration and All Kids Count (a national technical assistance center fostering development of integrated child health information systems) have been working together to develop an integrated child health information system. Activities have included: identification of key elements for successful integration of systems; development of principles and core functions for the systems; a survey of state and local integration efforts; and a conference to develop a common vision for child health information systems to meet medical care and public health needs. Researchers identified Utah as one state that is close to development of integrated child health information systems.

Hinman, Alan R., et al., "Linking Children's Health Information Systems: Clinical Care, Public Health, Emergency Medical Systems, and Schools," ***Pediatrics*** **123, Supplement no. 2 (January 2009): S67-S73.**
http://pediatrics.aappublications.org/content/123/Supplement_2/S67.full.pdf

> Summary: This article describes health information systems used for children in a variety of settings (e.g., clinical care, public health, emergency medicine systems, and schools) and their current ability to exchange information. The potential benefits from linking these systems are considered, as well as the barriers to linkage. In addition, an example of efforts linking information systems together is summarized, and conclusions are drawn from this example for future efforts.

Jensen, Roxanne E., "Implementing Electronic Health Record-Based Quality Measures for Developmental Screening," ***Pediatrics 124,*** **no. 4 (October 2009): e648-e654.**
http://pediatrics.aappublications.org/content/124/4/e648.full.pdf

> Summary: A group of pediatric clinicians and health informatics experts convened to develop quality indicators reflecting different aspects of the developmental screening process. These indicators included the administration of a standardized, validated instrument to screen children for developmental delays, the documentation of abnormal screening results, and the provision of follow-up care. They evaluated six integrated provider systems across the United States, with fully implemented EHR systems to determine the feasibility of implementing these measures within each system. Barriers related to measure implementation were identified. The EHR systems of all six health care organizations could implement measures examining developmental screening rates and could identify and track children with abnormal screening results. However, most of the systems did not have the ability to capture data for more complex EHR-based measures. In particular, data elements based on workflow actions could not be captured with current EHR system designs. This study identified two main barriers to the implementation of developmental quality measures: concerns about data reliability and the tracking of care coordination within patient records. Potential solutions to these problems, including terminology standardization, patient portal use, and use of a single developmental screening instrument, are discussed.

Low, David, "The National Programme for IT: Will It Be Good for Children?" ***Journal of Family Health Care*** **19, no. 6 (2009): 189-190.**

> Summary: Great Britain's National Health Service, Connecting for Health, set up a Child Health Programme in 2007 to map out and make the case for a common core content for EHRs. A record with a common core content, readily available for every child and parent or caregiver, and for each professional delivering their health care, would be an advantage. The basis of one already exists as the Personal Child Health Record. Systems are developing and are in operation in different parts of the country, which are beginning to share information between different health organizations as well as integrating different systems.

McDonald, Julia, et al., "Health Information Technology to Guide Pediatric Obesity Management," *Clinical Pediatrics* 50, no. 6 (June 2011): 543-549.

> Summary: The purpose of this study was to examine pediatricians' familiarity with expert committee recommendations on the management of childhood obesity and their use of health information technology for obesity-related care. Nearly all pediatricians were unfamiliar with expert recommendations; however, all participants reported using growth charts and providing nutrition and physical activity counseling. Most participants wanted easy access to educational materials they could print for patients. The majority of participants were in favor of an electronic alert to identify obese patients, remind clinicians of current guidelines, and facilitate ordering, believing it would help standardize care. Concerns included "alert fatigue," distraction, and disruption of workflow. Suggestions for future electronic functions included tailored educational materials and physical activity resources customized by patient address.

Menachemi, Nir, et al. 2006. Charting the Use of Electronic Health Records and Other Information Technologies among Child Health Providers. *BMC Pediatrics* 6: 21.
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1552060/

> Summary: Previous studies regarding the use of IT specifically among pediatricians and other physicians who treat children are lacking. As such, the objective of this study was to examine the use of EHR systems and other IT applications among pediatricians and other child health providers (CHPs) in Florida. Researchers compared general pediatricians to other CHPs and all CHPs (including pediatricians) to other physicians with respect to computer and internet availability, and to the use of personal digital assistants and EHRs. General pediatricians (13.7%) were significantly less likely to be using an EHR than both CHP family physicians (26.1%) and pediatric sub-specialists (29.6%). Researchers found that physicians caring for children, and especially pediatricians, in Florida, are significantly slower than other doctors to adopt EHRs and important electronic patient safety functionalities into their practices.

Menachemi, Nir, et al., "Influence of Pay-for-Performance Programs on Information Technology Use among Child Health Providers: The Devil Is in the Details," *Pediatrics* 123, Supplement no. 2 (January 2009): S92-S96.
http://pediatrics.aappublications.org/content/123/Supplement_2/S92.full.pdf

> Summary: This study explored how various pay-for-performance compensation methods are related to HIT use among CHPs practicing in Florida. The most common reported method to affect respondents' compensation was traditional productivity or billing (78%). Pay-for-performance programs linking measures of clinical quality to compensation were positively associated with personal digital assistant use among child health providers. Pay-for-performance programs that do not directly emphasize HIT use do not influence the adoption of electronic health records among Florida physicians treating children. Understanding how different pay-for-performance compensation methods incentivize HIT adoption is important for improving quality.

Miles, Paul V., et al., "Alliance for Pediatric Quality: Creating A Community of Practice To Improve Health Care For America's Children," ***Pediatrics*** **123, Supplement no. 2 (January 2009): S64-S66.**
http://pediatrics.aappublications.org/content/123/Supplement_2/S64.full.pdf

> Summary: This article describes the work and achievements of the Alliance for Pediatric Quality. Each member in the alliance represents a children's hospital or pediatric practice affiliated with one of the 4 major national pediatric organizations that constitute the Alliance for Pediatric Quality. The alliance works with the pediatric health information technology community to speed the adoption of pediatric data standards and to define data collection and reporting systems that would work for both quality improvement and EHR systems. With this foundation, hospitals and physicians should be better positioned to improve the quality of health care for U.S. children by implementing technology equipped to care for children, actively participating in improvement initiatives, conducting meaningful measurement of care, and appropriately reporting for accountability.

Miller, Amalia, et al., "Can Health Care Information Technology Save Babies?" ***Journal of Political Economy*** **119, no. 2 (April 2011): 289-384.**

> Summary: EMRs facilitate fast and accurate access to patient records, which could improve diagnosis and patient monitoring. Using a 12-year county-level panel, researchers found that a 10% increase in births that occur in hospitals with EMRs reduces neonatal mortality by 16 deaths per 100,000 live births. This is driven by a reduction of deaths from conditions requiring careful monitoring. Researchers also found a strong decrease in mortality when they instrumented for EMRs adoption using variation in state medical privacy laws. Rough cost-effectiveness calculations suggest that EMRs are associated with a cost of $531,000 per baby's life saved.

Morrow, Beth, ***Emerging Health Information Technology for Children in Medicaid and SCHIP Programs*****, The Children's Partnership (November 2008): 1-38.**
http://www.childrenspartnership.org/storage/documents/Publications/emerginghealthinfotech.pdf

> Summary: This report finds that states are innovators, utilizing HIT in their Medicaid and State Children's Health Insurance Program (SCHIP) programs across the range of program functions, from outreach and enrollment, and service delivery and care management to communications with families, and broader program planning and improvement. Though many of these HIT efforts are still in their infancy and data on their impact is limited, early findings indicate improvements in access to care, care coordination, case management, and administrative efficiency. This Snapshot is not an exhaustive summary of Medicaid and SCHIP HIT activity, but rather a sampling of efforts that offer states a range of replicable, promising approaches to improve children's health. Based on interviews with state HIT leaders and national experts, it introduces policymakers, program planners, and other key stakeholders to the variety of HIT

opportunities available to improve Medicaid and SCHIP and provides a roadmap for moving ahead with new HIT tools.

Morrow, Beth, *Maximizing the Value of HIT to Improve the Health of Children: A Guide for Consumer Engagement*, The Children's Partnership (September 2011): 1-4.
http://www.childrenspartnership.org/storage/documents/Publications/Child_Consumer_Engagement_HIT_Guide_9.9.11Final2.pdf

Summary: This document lays out four guideposts that should govern any HIT effort to engage the consumer in their own care, with a specific focus on the unique needs of children and their parents. It also identifies core functions that can maximize the value and utility of any HIT tool that collects information from or provides information to a child and parent, such as through a PHR, a patient portal into a health care provider's EHR, or a mobile monitoring device.

Ngo-Metzer, Quyen, "Improving Communication Between Patients and Providers Using Health Information Technology and Other Quality Improvement Strategies: Focus on Low-Income Children," *Medical Care Research and Review* 67, Supplement no. 5 (July 2010): 246S-267S.

Summary: The authors conducted a systematic review of the literature on studies of communication surrounding the care of low-income children, with an emphasis on interventions and HIT. The search yielded six studies that focused on low-income children; three of the studies used health IT. Key informant interviews provided insight to the current use of HIT for provider-patient communication in geographically diverse, under-resourced settings. The authors identified gaps between existing literature and clinical practice. Future research should focus on the specific impact of HIT in pediatric medicine, particularly in under-resourced and safety-net settings. These efforts should focus on the use of technological innovations to improve care for low-income children and their families.

Pfister, Helen, et al., *Privacy Please: Health Consent Laws for Minors in the Information Age*, Manatt Health Solutions, prepared for the California Health Care Foundation, January 2013: 1-8.
http://tinyurl.com/bwwj799

Summary: This report provides an overview of the laws governing disclosure of minors' health information and spotlights the challenges that these laws pose to a comprehensive electronic information exchange.

Slagle, Jason M., et al., "MyMediHealth--Designing a Next Generation System for Child-Centered Medication Management," *Journal of Biomedical Informatics* 43, Supplement no. 5 (October 2010): S27-S31.

> Summary: PHR and emerging user-adopted communication tools promise to change the landscape of medication management. However, no research has been done to demonstrate how these tools might be constructed to support children with special health care needs. The overarching goal of the MyMediHealth project was to investigate ways in which PHRs and supported applications can improve the safety and quality of medication delivery in this population. Researchers have completed a working prototype of a scheduling system, a text-message-based alert and reminder system, and a medication administration record based on web-entered patient data. Pilot testing of the working prototype by stakeholders yielded strong endorsement and helpful feedback for future modifications, which are now underway as a part of an expanded project to test this system in a real-world environment.

Spooner, S. Andrew, "Special Requirements of Electronic Health Record Systems in Pediatrics," *Pediatrics* 119, No. 3 (March 2007): 631-637.

> Summary: Some functions of an EHR system are much more important in providing pediatric care than in adult care. Pediatricians commonly complain about the absence of these "pediatric functions" when they are not available in EHR systems. To stimulate EHR vendors to recognize and incorporate pediatric functionality into pediatric EHR systems, this clinical report reviews the major functions of importance to child health care providers. Also reviewed are important but less critical functions, any of which might be of major importance in a particular clinical context. The major areas described here are immunization management, growth tracking, medication dosing, data norms, and privacy in special pediatric populations. The American Academy of Pediatrics believes that if the functions described in this document are supported in all EHR systems, these systems will be more useful for patients of all ages.

Stahl, Ylva, et al. 2011. Views on Health Information and Perceptions of Standardized Electronic Records among Staff in Child and School Health Services. *Journal of Nursing Management* 19: 201-208.

> Summary: An investigation into how nurses and physicians in Sweden's Child and School Health Services view the documentation and transfer of health information. Another aim concerns their perceptions of a nationally standardized EHR. There was a consensus concerning the usefulness of a nationally standardized electronic health record, although there were group differences between nurses and physicians. All information about children's health is not documented although the professional's positive perceptions to EHRs may provide a basis to improve documentation. Results indicate challenges to develop a common language to document psychosocial issues necessary for providing a holistic view of children's health.

Tintsman, Thomas, et al., *Behavioral Health IT: Toward Seamless Care for California's Kids*, Health Technology Center, prepared for the California HealthCare Foundation, (March 2009): 1-23
http://tinyurl.com/d8qfddv

> Summary: This report examines the current status, challenges, and opportunities for behavioral health information systems, particularly EHRs and PHRs, which support government-sponsored mental health services for children and adolescents in California. It focuses on young people because they are the most diverse segment of the mental health care population in terms of their service needs and the array of provider types that serve them.

Vest, Joshua R., et al. 2011. Use of a Health Information Exchange System in the Emergency Care of Children. *BMC Medical Informatics and Decision Making* 11: 78.
http://www.biomedcentral.com/content/pdf/1472-6947-11-78.pdf

> Summary: Children may benefit greatly in terms of safety and care coordination from the information sharing promised by HIE. Using data from an operational HIE effort in central Texas, researchers examined the factors associated with actual system usage. Users accessed the system for 8.7% of encounters. Increasing patient comorbidity was associated with a 5% higher odds of basic usage and 15% higher odds for novel usage. The odds of basic system usage were lower in the face of time constraints and for patients who had not been to that location in the previous 12 months. HIE systems may be a source to fulfill users information needs about complex patients. However, time constraints may be a barrier to usage. In addition, results suggest HIE is more likely to be useful to pediatric patients visiting the emergency department repeatedly. This study helps fill an existing gap in the study of technological applications in the care of children and improves knowledge about how HIE systems are utilized.

Foster Youth:

Chisolm, Deena, "Development of a Computerized Medical History Profile for Children in Out-Of-Home Placement Using Medicaid Data," *Journal of Health Care for the Poor and Underserved* 20, No. 3 (August 2009): 748-755.
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2938782/

> Summary: This report describes the development of a medical history profile, or passport, developed from Medicaid administrative data. A purposive sample of 25 youths was provided from a county child protective services agency. The patients were systematically matched with data from the state Medicaid agency. Using Medicaid claims/encounter data, researchers generated health care profiles that provided information on historical use of ambulatory care, diagnoses, providers seen, medications used, and in-patient admissions. Profiles were, however, limited by missing provider information and non-specific diagnostic coding. Despite these limitations, Medicaid data-based profiles show the potential to be a cost-efficient method for improving continuity of care for children in out-of-home placement.

Gluckman, Stephanie, et al., *From Silos to Linkages: Improving Outcomes for Vulnerable Youth through the Wise Use of Information Technology*, The Children's Partnership (May 2011): 1-19.
http://tinyurl.com/d22af7u

> Summary: This brief summarizes key efforts that are currently underway in California to improve outcomes for children in foster care through the use of information technology. The brief also addresses how these efforts can be leveraged to allow California to move toward an environment of interoperable systems that will allow for efficient and effective care coordination.

Gluckman, Stephanie, et al., *Improving the Health Outcomes for Children in Foster Care: The Role of Electronic Record Systems*, The Children's Partnership (October 2008): 1-20.
http://www.childrenspartnership.org/storage/documents/Publications/FosterCareIssueBrief-full.pdf

> Summary: The issue brief provides policy leaders with information about the way Electronic Records Systems (ERSs), when applied appropriately, can benefit children in foster care and the systems that serve them. Specifically, the brief examines the need for improved information collection and sharing in the provision of health care services to children in foster care; provides an overview of the ways ERSs can be and are being used to improve health outcomes for children in foster care; highlights early evidence of the impacts of these efforts; outlines lessons learned from these efforts about system development, capacity, privacy issues, and funding streams; and highlights strategies used to expand the use of ERSs to greater numbers of children in foster care.

Frear, Meghan, *Health Information Exchange Breakthrough Goal: The Use of Personal Health Records in Foster Children and Long-Term Care Patients*, Prepared for the CHHS Health Information Exchange, Update on ONC Bold Audacious Goal, September 2011: 1-16.
http://tinyurl.com/curcv6y

> Summary: The author provides an update on the progress of the CHHS Information Exchange towards a personal electronic health care record system for foster youth and long-term care patients. Highlights include short summaries of existing and pilot PHR projects, and the barriers to success, particularly privacy and security issues for both patient groups.

Hansen, Robin L., et al., "Comparing the Health Status of Low-Income Children in and Out of Foster Care," *Child Welfare* 83, no. 4 (July/August 2004): 367-380.

> Summary: This study compared the overall health status of a group of children entering foster care with a group of Medicaid-eligible children living with their parents, matched for age and gender. It identified significantly more health and developmental problems in children in foster care than in the comparison group. Possible contributors to the higher

percentage of problems among foster care children may be that the foster care children have more underlying risk factors resulting in placement, or that the foster care physicians conducted a more comprehensive assessment or had lower clinical thresholds. Further research is necessary to identify and treat the problems of this high-risk group.

Mekonnen, Robin, et al. 2009. Achieving Better Outcomes for Children in Foster Care. *Pediatric Clinics of North America* 56: 405 -- 415.

Summary: This article reviews the challenges health care systems have faced as they have attempted to improve health care outcomes for children in foster care. It discusses several of the promising health care strategies occurring outside the perimeter of child welfare and identifies some of the key impasses in working alongside efforts in child welfare reform. The central thesis of this article is to demonstrate the implausibility of improving health-related outcomes for children in foster care without fundamentally addressing the impact of frequent placement disruptions on the lives and well-being of children. Finally, the authors propose potential strategies for targeting incremental reform efforts, specifically involving placement stability, as a vehicle for multi-disciplinary reform inclusive of the health care system.

Morrow, Beth, *Electronic Information Exchange: Elements That Matter for Children in Foster Care*, The Children's Partnership (January 2013): 1-10.
http://www.childrenspartnership.org/storage/documents/Publications/Electronic_Information_Exchange.pdf

Summary: Electronic information exchange has the potential to improve care coordination for children, particularly those who have complex health and social needs such as children in foster care. This primer lays out the case for investing in systems that enable such exchange, reviews existing efforts underway in states and communities, identifies specific elements that serve this population most effectively, and discusses issues that need to be addressed and steps that can be taken to make the most of this opportunity.

Schneiderman, Janet U., et al., 2011. Pediatric Health Assessments of Young Children in Child Welfare by Placement Type. *Child Abuse & Neglect* 35: 29-39.

Summary: This study describes health-related problems across placement types (unrelated foster, kin foster, in-home with birth parent) and examines the association of placement and demographic/child welfare variables (child gender, age, race/ethnicity; caregiver language; type of maltreatment, and length of time receiving services from child welfare) with health-related problems. This study utilized a retrospective medical chart review of children less than 6 years old seen at an outpatient child welfare pediatric clinic. Almost 13% of children in the sample were obese and more than a quarter were overweight/obese, while only 7% were underweight. Most children (78%) had a physical health diagnosis and 25% were provisionally identified with a developmental delay. Results argue for careful assessment of weight, medical, and developmental problems in children active in child welfare, whether residing in their home of origin, with kin, or with unrelated foster parents. The comprehensive health examination and enhanced health maintenance schedule for children in foster care should be extended to children who remain at home with child welfare services as child welfare involvement rather than placement is related to health-related problems.

Talbot, John F., "PHR's Fill Role of Health Passport for Foster Kids," ***The Open Minds Circle*** **(October 2010): 1.**
http://tinyurl.com/btq3zdb

Summary: HealthShack, developed by the Sierra Health Foundation, with input from foster youth, is one example of a PHR that contains more than just medical data. This system contains education, job and residence information -- and participating foster care youth have control over who sees this information.

Veterans:

Bouhaddou, Omar, et al., "Toward a Virtual Lifetime Electronic Record: The Department Of Veterans Affairs Experience with the Nationwide Health Information Network," In ***American Medical Informatics Association Annual Symposium Proceedings*** **(2012): 51-60.**
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3540491/

Summary: HIE is expected of all EHRs in order to ensure safe, quality care coordination. The VA has a long history of information exchange across VA facilities and with the DoD. However, since a majority of VA and DoD patients receive a portion of their health care from the private sector, it is essential that both agencies enable HIE with private sector providers. This process has been made possible by the use of the specifications and trust agreement developed by the NwHIN initiative. Currently, the VA has 12 medical centers exchanging information with the private sector and is evaluating the value of the exchange. The authors report on the success of these pilots as well as on the challenges, which include stricter technical specifications and a more efficient approach to patient identification matching and consent management.

Byrne, Colleen M., et al., "The Value from Investments in Health Information Technology at the U.S. Department Of Veterans Affairs," ***Health Aff*****airs 29, No. 4 (April 2010): 629-638.**
http://content.healthaffairs.org/content/29/4/629.full.pdf+html

Summary: A comparison of HIT in the VA to norms in the private sector, and an estimate of the costs and benefits of selected VA health IT systems finds that the VA spent proportionately more on IT than the private health care sector spent, but it achieved higher levels of IT adoption and quality of care. The potential value of the VA's health IT investments is estimated at $3.09 billion in cumulative benefits net of investment costs. This study serves as a framework to inform efforts to measure and calculate the benefits of federal health IT stimulus programs.

Chumbler, Neale R., et al., "Implementation of Health Information Technology in Veterans Health Administration to Support Transformational Change: Telehealth and Personal Health Records," ***Medical Care*** **48, No. 2 (December 2011): S36-S42.**

> Summary: The VHA has developed a PHR, MHV, which is a secure web-based portal that provides veterans the capability to access and manage health information. This article discusses the mechanisms by which these forms of HIT have been implemented to improve access to care and improve health. For Telehealth, the researchers present the outcomes from some of the published literature. For PHRs, they outline what is known to date and future research directions. The article also examines some structural, policy-related, and organizational barriers to health IT implementation and offers suggestions for future research.

Do, Nhan V., et al., "The Military Health System's Personal Health Record Pilot with Microsoft Healthvault and Google Health," ***Journal of the American Medical Informatics Association*** **18, no. 2 (March-April 2011): 118-124.**
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3116258/

> Summary: A pilot project was conducted in 2008-2009 at Madigan Army Medical Center in Tacoma, Washington using Microsoft Healthvault and Google Health. The project design and implementation were guided by provider and patient advisory panels with formal user evaluation. Key lessons learned related to data-transfer decisions (push vs. pull), purposeful delays in reporting sensitive information, understanding and mapping PHR use and clinical workflow, and decisions on information patients may choose to share with their provider. Currently PHRs are being viewed as empowering tools for patient activation. Design and implementation issues (e.g., technical, organizational, information security) are substantial and must be thoughtfully approached. Adopting standards into design can enhance the national goal of portability and interoperability.

Goldzweig, Caroline L., et al., ***Systematic Review: Secure Messaging between Providers and Patients, and Patients' Access to Their Own Medical Record: Evidence on Health Outcomes, Satisfaction, Efficiency and Attitudes,*** **Evidence-Based Synthesis Program, U.S. Department of Veterans Affairs, July 2012: 1-4.**
http://www.hsrd.research.va.gov/publications/esp/myhealthevet-EXEC.pdf

> Summary: As the VHA expands the capabilities of its personal health record system, MHV, and places greater emphasis on encouraging its use, it is interested in understanding how best to prioritize different functionalities and which of them will provide the greatest benefits to Veterans. This systematic review was designed to evaluate the literature surrounding secure messaging systems and electronic applications that give patients access to their own medical records, specifically investigating the evidence that these systems improve health outcomes, patient satisfaction, healthcare utilization and efficiency, and adherence. Additionally, the authors examined studies that evaluated attitudes, particularly regarding patients having online access to their own medical information. The review distinguished between electronic systems that were

"tethered" or tied to existing healthcare institution systems similar to how MHV is tethered to VHA's EHR, versus those that were "stand-alone."

Haggstrom, David A., et al., "Lessons Learned from Usability Testing of The VA's Personal Health Record," ***Journal of the American Medical Informatics Association*** **18, Supplement no. 1 (December 2011): i13-i17.**
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3241159/

Summary: Observational videos and efficiency measures were collected among users performing four PHR scenarios: registration and log-in, prescription refill, tracking health, and searching for health information. The results included that 25% of users successfully completed registration, and individuals preferred prescription numbers over names, sometimes due to privacy concerns. Only efficiency in prescription refills was significantly better than target values. Also, users wanted to print their information to share with their doctors, and questioned the value of MHV search functions over other existing online health information systems.

Hogan, Timothy P., et al., "Promoting Access through Complementary Ehealth Technologies: Recommendations for VA's Home Telehealth and Personal Health Record Programs," ***Journal of General Internal Medicine*** **26, Supplement no. 2 (November 2011): 628-635.**
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3191221/

Summary: Using the VA as a case study, this paper presents two specific eHealth technologies: Care Coordination Home Telehealth (CCHT) Program and the MHV PHR portal with integrated secure messaging. The paper articulates a vision of how they might be implemented as part of a patient-centric healthcare model and used in a complementary manner to enhance access to care and to support patient-centered care. The VA's CCHT and MHV programs are examples of an expanding repertoire of eHealth applications available to patients and healthcare teams. The VA's new patient-centric healthcare model represents a significant shift in the way that services are delivered and a profound opportunity to incorporate eHealth technologies like the CCHT and MHV programs into clinical practice to increase access to care, and to ensure the responsiveness of such technologies to the preferences and circumstances of patients.

Nazi, Kim M., et al., "Embracing a Health Services Research Perspective on Personal Health Records: Lessons Learned from the VA My Healthevet System," ***Journal of General Internal Medicine*** **25, Supplement no. 1 (January 2010): 62-67.**
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2806958/

Summary**:** Drawing from the experiences of VA staff to evaluate the MHV PHR, this article advocates for a health services research perspective on the study of PHR systems. Researchers describe an organizing framework and research agenda, and offer insights that have emerged from our ongoing efforts regarding the design of PHR-related studies, the need to address PHR data ownership and consent, and the promotion of effective

PHR research collaborations. These lessons are applicable to other PHR systems and the conduct of PHR research across different organizational contexts.

Nazi, Kim M., et al., "Myhealthevet PHR: A Description of Users and Patient Portal Use," In *American Medical Informatics Association Annual Symposium Proceedings* (November 2008): 1182.

Summary: The MHV PHR continues to demonstrate significant growth, with more than 630,000 registered users logging more than 20 million visits to the site. Understanding patient user characteristics, use of and satisfaction with current features, and desires for new online services reveals important user perceptions that will further inform PHR development.

U.S. Congress. House of Representatives. U.S. House Veterans' Affairs Subcommittee on Disability Assistance and Memorial Affairs. *Wading through Warehouses of Paper: The Challenges of Transitioning Veterans Records to Paperless Technology.* 112th Congress, December 4, 2012.
http://veterans.house.gov/witness-testimony/mr-jim-neighbors-0

Summary: This testimony covers how the DoD captures and transfers to the VA, Medical and Personnel records for Active and Reserve Component Service members while in deployed or in garrison status. As these organizations move toward electronic exchange of information in real time, it is giving DoD and VA the added benefit of improving inter-agency processes based on information requirements, unencumbered by legacy forms or manual, paper-based exchange of information.

Schneider, Janet M., "Electronic and Personal Health Records: VA's Key to Patient Safety," *Journal of Consumer Health on the Internet* 14, No. 1 (January-March 2010): 12-22.

Summary: This article outlines different types of EHRs and their uses, barriers to implementation, and issues patients should be aware of when contemplating compiling their own PHRs. A case report of the VHA explains how it is moving toward an integrated health record that enhances patient safety and informed health care options.

Turvey, Carolyn L., et al., "Transfer of Information from Personal Health Records: A Survey Of Veterans Using My Healthevet," *Telemedicine Journal and E Health* 18, no. 2 (March 2012): 109-114.

Summary: MHV is a Web-based patient portal containing a personal health record administered by the VHA. The goal of this study was to explore veterans' interest and use of MHV to transfer and share information as well as to identify opportunities to increase veteran use of the MHV functions. Two waves of data were collected in 2010 through an American Customer Satisfaction Index Web-based survey. Wave One results found that 41% of veterans reported printing information, 21% reported saving information electronically, and only 4% ever sent information from MHV to another person. In Wave

Two, 30% reported self-entering medication information, with 18% sharing this information with their VA provider and 9.6% sharing with their non-VA provider. Although veterans are transferring important medical information from their personal health records, increased education and awareness are needed to increase use. PHRs have the potential to improve continuity of care. However, more research is needed on both the barriers to adoption as well as the actual impact on patient health outcomes and well-being.

Other Vulnerable Populations:

Ancker, Jessica S., et al., "Use of an Electronic Patient Portal Among Disadvantaged Populations," ***Journal of General Internal Medicine*** **26, no. 10 (October 2011): 1117-1123.**
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3181304/

Summary: The purpose of this study was to quantify electronic portal usage and explore potential differences in adoption and use according to patients' socioeconomic and clinical characteristics in a network of federally qualified health centers serving New York City and neighboring counties. Researchers found good early rates of adoption and use of an electronic patient portal during the first two years of its deployment among a predominantly low-income population, especially among patients with chronic diseases. Disparities in access to and usage of the portal were evident but were smaller than those reported recently in other populations. Continued efforts will be needed to ensure that portals are usable for and used by disadvantaged groups so that all patients benefit equally from these technologies.

Botts, Nathan E., et al., "Electronic Personal Health Records and Systems to Improve Care for Vulnerable Populations," In ***American Medical Informatics Association Annual Symposium Proceedings*** **(October 2007): 880.**

Summary: The efforts of this research are to educate patients within vulnerable populations in the use of electronic personal health records so they may better monitor their health, attain desired health goals and manage their health services. Evaluation measures will include facets of self-management of health, patient-physician communication, and assessment of accessibility and usability factors of the personal health record.

Crilly, John F., et al., "Use of Electronic Technologies to Promote Community and Personal Health for Individuals Unconnected to Health Care Systems," ***American Journal of Public Health*** **101, no. 7 (July 2011):1163-1167.**

Summary: Ensuring health care services for populations outside the mainstream health care system is challenging for all providers. But developing the health care infrastructure to better serve such unconnected individuals is critical to their health care status, to third-party payers, to overall cost savings in public health, and to reducing health disparities. Increasingly sophisticated electronic technologies offer promising ways to more effectively engage this difficult-to-reach group and increase its access to health care resources. This process requires developing not only newer technologies but also collaboration between community leaders and health care providers to bring unconnected individuals into formal health care systems. The researchers present three strategies to reach vulnerable groups, outline benefits and challenges, and provide examples of successful programs.

Dang, Michelle T., et al., "A Web-Based Personal Health Information System for Homeless Youth and Young Adults," *Public Health Nursing* 29, no. 4 (July-August 2012): 313-319.

Summary: Runaway and homeless youth face multiple challenges to their health and experience inadequate access to health care services. This article describes a web-based personal health information system (PHIS) called Healthshack that was specifically designed to improve health care access and health outcomes for runaway and homeless youth at a community-based agency that served homeless youth and young adults up to age 24. The program was developed in partnership with homeless youth and piloted by public health nurses. Preliminary findings from the program indicate that a PHIS is acceptable to runaway and homeless youth and feasible to incorporate into the flow of a youth agency. Thus, a PHIS may be an innovative model of service delivery for other marginalized populations.

Fetter, Marilyn S., "Personal Health Records: Protecting Behavioral Health Consumers' Rights," *Issues in Mental Health Nursing* 30, no. 11 (November 2009): 720-722.

Summary: PHRs can empower health consumers and inform population health. HIT is seen as a transformative policy in mental health and substance abuse treatment and prevention. Security of electronic health data is a worry among providers, patients and regulators. Concerns include identity theft, employer notification, release of information to insurers, and availability to marketers. The author discusses philosophical concerns about competing models of data push and data pull and practical methods of patient education about privacy protection.

Fonda, Stephanie J., et al., "Combining iGoogle and Personal Health Records to Create a Prototype Personal Health Application for Diabetes Self-Management," *Telemedicine and e-Health* 16, no. 4 (May 2010): 480-489.

Summary: The aim of this project was to create a prototype for a personal health application (PHA) for patients (i.e., consumers) with diabetes by employing a user-centered design process. Focus group participants said they wanted a tool that could give them timely, readily available information on how diabetes-related domains interact, how their behaviors affect them, and what to do next. Thus, the prototype PHA is Internet-based, retrieves data for diabetes self-management from a personal health record, displays that data using gadgets in the consumer's iGoogle page, and makes the data available to a decision-support component that provides lifestyle-oriented advice. Manipulation of the data enables consumers to anticipate the results of future actions and to see interrelationships. A user-centered design process resulted in a PHA that uses publicly available technology, employs a personal health record, and is Internet based.

This PHA can provide the backbone for a decision support system that can bring together the cornerstones of diabetes self-management and integrate them into the life of the person with diabetes.

Fowles, Eileen R., et al., "The Feasibility of Personal Digital Assistants (PDAs) to Collect Dietary Intake Data in Low-Income Pregnant Women," ***Journal of Nutrition Education and Behavior*** **40, no. 6 (November-December 2008): 374-377.**

Summary: The purpose of this study was to determine the feasibility of using PDA-based technology for tracking and analysis of food intake in low-income pregnant women. Participants provided an initial 24-hour dietary recall and recorded their food intake using a PDA-based software program for 2 days. The PDA was significantly easier to use compared to the 24-hour recall, and no significant differences in ease of remembering food intake between these methods was noted. Most women liked the PDA and felt it was more accurate than 24-hour recalls. PDA-based software may be an acceptable method for obtaining food records to provide more accurate assessments of dietary intake in this vulnerable population.

Hargreaves, John S., "Will Electronic Personal Health Records Benefit Providers and Patients in Rural America?" ***Telemedicine and E Health*** **16, no. 2 (March 2010): 167-176.**

Summary: The objective of this study was to educate stakeholders (e.g., providers, patients, insurers, government) in the healthcare industry about electronic PHRs and their potential application in rural America. Extensive research was performed on PHRs through standard literature search, product demonstrations, educational webinars, and fact finding via news releases. It remains to be seen if barriers to adoption, including privacy concerns, lack of interoperability standards and funding, and provider resistance, can be overcome to enable PHRs to become a critical tool in the creation of a more efficient and less costly U.S. healthcare industry. Electronic PHRs hold great promise to enhance access and improve the quality of care provided to patients in rural America. Government, vendors, and insurers should create incentives for providers and patients to implement PHRs. Likewise, patients need to become more aware of PHRs and their ability to improve health outcomes.

Lyles, Courtney R., et al., "Patient Race/Ethnicity and Shared Medical Record Use Among Diabetes Patients," ***Medical Care*** **50, no. 5 (May 2012): 434-40.**

Summary: Previous studies have documented racial/ethnic differences in patients' use of websites providing shared electronic medical records between patients and health care professionals. Less is known about whether these are driven by patient-level preferences and/or barriers versus broader provider or system factors. This paper summarizes a cross-sectional study of diabetes patients in an integrated delivery system in 2008-2009. Primary measures were race/ethnicity and shared medical record (SMR) use. The majority (62%) of Whites used the SMR, compared with 34% of Blacks, 37% of Asians, and 55% of other race/ethnicity. Most respondents (76%) stated that their provider had encouraged them to use the SMR, with no differences by race/ethnicity. Among diabetes patients, differences in SMR use by race/ethnicity were not fully explained by differences in age, sex, sociodemographics, health status, or provider factors-particularly for Black patients. There were few racial/ethnic differences in provider encouragement or provider secure messaging use that would have suggested disparities at the provider level.

Malone, Michael L., et al., "AcuteCare for Elders (ACE) Tracker and e-Geriatrician: Methods to Disseminate ACE Concepts to Hospitals with No Geriatricians on Staff," ***Journal of the American Geriatrics Society*** **58, no. 1 (January 2010): 161-167.**

Summary: This article describes an innovative method to disseminate the Acute Care for Elders (ACE) model of care for hospitalized older patients implemented at 11 community hospitals in Wisconsin. The ACE Tracker is a computer-generated checklist of all older patients in a facility that takes information from multiple areas of the electronic medical record to identify the older patients' risk factors for functional decline and poor outcomes. The effect of the ACE Tracker and e-Geriatrician models was assessed by measuring use of urinary catheters, physical restraints, high-risk medications, and social service evaluation at a single hospital for the 6 months before and after implementation of the models. There were significant improvements in urinary catheter and physical therapy referrals but no significant changes in the other outcomes. There was no change in the length of stay or in the rate of hospital readmission within 30 days.

McInnes, Keith D., et al. "Use of Electronic Personal Health Record Systems to Encourage HIV Screening: An Exploratory Study of Patient and Provider Perspectives." ***BMC Research Notes*** **4, no. 295 (August 2011).**
http://www.biomedcentral.com/1756-0500/4/295 **(accessed May 8, 2013).**

Summary: Researchers sought to evaluate the optimal circumstances and conditions for outreach about HIV screening. In an exploratory, qualitative research study they examined patient and provider perceptions of Internet-based outreach to increase HIV screening among veterans who use the VHA health care system. Patients and providers indicated that electronic outreach through a PHR would provide useful information and would motivate patients to be screened for HIV. Patients believed that electronic information would be more convenient and understandable than information provided verbally. There is considerable potential to use PHR systems for electronic outreach and social marketing to communicate to patients about, and increase rates of, disease screening, including for HIV. Planning for direct-to-patient communications through PHRs should include providers and address provider reservations, especially about workload increases.

Mitchell, B., et al. "Electronic Personal Health Records That Promote Self-Management in Chronic Illness." ***OJIN: The Online Journal of Issues in Nursing*** **15, No. 3 (July 20, 2010).** http://www.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/Vol152010/No3-Sept-2010/Articles-Previously-Topic/Electronic-Personal-Health-Records-and-Chronic-Illness.html **(accessed May 8, 2013).**

> Summary: A growing trend in self-management is to offer patients access to their health information through the use of electronic PHRs. However, there needs to be a match between patients' health literacy levels and the PHR software used in electronic PHRs to effectively promote self-management. In this article the authors use Chronic Obstructive Pulmonary Disorder (COPD) as an example of a chronic illness that can be self-managed through the use of electronic PHRs. They begin by providing overviews of COPD management, self-management, health literacy and the use of electronic personal health records as self-management tools. Then they draw upon Nutbeam's health literacy framework to guide healthcare providers in matching a patient's health literacy level with a software program appropriate for a particular patient.

Purvis, Suzanne, et al., "Innovative Use of Electronic Health Record Reports by Clinical Nurse Specialists," ***Clinical Nurse Specialist*** **CNS 24, no.6 (November-December 2010): 289-294.**

> Summary: The purpose of the study was to demonstrate how clinical nurse specialists (CNSs) can use information pulled from the EHR in innovative ways to improve nursing care of vulnerable older adults. Clinical information from various parts of the EHR is pulled into computer-generated reports that focus on identifying older adult patients with specific high-risk indicators. Computerized reports can be used to facilitate the use of nursing practice guidelines and evidence-based clinical tools such as the confusion assessment method and to increase use of nursing plans of care. The reports can also provide real-time key indicators that can be used to facilitate identification of older adult patients in need of CNS and/or geriatric team consultation. More research still needs to be done regarding the impact of the EHR on nursing indicators such as number of falls, delirium, and use of restraints.

Sarkar, Urmimala U., et al., "Social Disparities in Internet Patient Portal Use in Diabetes: Evidence that the Digital Divide Extends Beyond Access," ***Journal of American Medical Informatics Association*** **18, no. 3 (2011): 318-321.**
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3078675/

> Summary: The authors investigated use of the internet-based patient portal, http://www.kp.org, among a well-characterized population of adults with diabetes in Northern California. Among 14,102 diverse patients, 5671 (40%) requested a password for the patient portal. Of these, 76% activated their accounts, and 69%, logged on to the patient portal one or more times; 53% of participants viewed laboratory results, 38% requested medication refills, 37% sent email messages, and 15% made medical appointments. After adjustment for age, gender, race/ethnicity, immigration status, educational attainment, and employment status, compared to non-Hispanic Caucasians,

African-Americans and Latinos had higher odds of never logging on, as did those without an educational degree (compared to college graduates). Those most at risk for poor diabetes outcomes may fall further behind as health systems increasingly rely on the internet and limit current modes of access and communication.

Tenforde, Mark, et al., "The Value of Personal Health Records for Chronic Disease Management: What Do We Know?" ***Family Medicine*** **43, no. 5 (May 2011): 351-354.**
http://www.stfm.org/fmhub/fm2011/May/Mark351.pdf

Summary: Electronic PHRs allow patients access to their medical records, self-management tools, and new avenues of communication with their health care providers. They will likely become a valuable component of the primary care Patient-Centered Medical Home model. Primary care physicians, who manage the majority of chronic disease, will use PHRs to help patients manage their diabetes and other chronic diseases requiring continuity of care and enhanced information flow between patient and physician. In this brief report, the authors explore the evidence for the value of PHRs in chronic disease management.

Yamin, Cyrus K., "The Digital Divide in Adoption and Use of a Personal Health Record," ***Archives of Internal Medicine 171,*** **no. 6 (2011): 568-574.**
http://archinte.jamanetwork.com/article.aspx?articleid=226918

Summary: The "digital divide," the population-level gap in Internet and computer access, may prevent certain groups from accessing PHRs. Researchers conducted a cross-sectional analysis of a PHR within a northeastern health system. They found that Blacks and Hispanics were less likely to adopt the PHR compared with whites, and those with lower annual income were less likely to adopt the PHR than were those with higher income. Compared with non-adopters, adopters were more likely to have more than 2 comorbidities. Despite increasing Internet availability, racial/ethnic minority patients adopted a PHR less frequently than white patients, and patients with the lowest annual income adopted a PHR less often than those with higher incomes. Among adopters, however, income did not have an effect on PHR use.

Yeager, Valerie A., et al., "EHR Adoption Among Doctors Who Treat the Elderly," ***Journal of Evaluation in Clinical Practice*** **16, no. 6 (December 2010): 1103-1107.**

Summary: This analysis contributes to the EHR adoption literature by determining if doctors who disproportionately treat the elderly differ from their counterparts with respect to the utilization of an important quality-enhancing health information technology application. This study is based on a primary survey of a large, statewide sample of doctors practicing in outpatient settings in Florida. Specifically, compared with their counterparts, HVE (high volume elderly) doctors were observed to be 26.7% less likely to be utilizing an EHR system. We also found that doctor age is negatively related to EHR adoption, and practice size and doctor computer savvy-ness is positively associated. Despite the fact that EHR adoption has improved in recent years, doctors in Florida who serve the elderly are less likely to adopt EHRs. As long as HVE doctors are adopting

EHR systems at slower rates, the elderly patients treated by these doctors will be at a disadvantage with respect to potential benefits offered by this technology.