

Annotated Bibliography

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Annotated Bibliography

Consumer Engagement in use of a Personal Health Record or e-Portal

These materials may be distributed to others without charge but should include the following credit:

This material was developed for the MN Community Measurement through the Robert Wood Johnson Foundation's Aligning Forces for Quality initiative

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Access to PHRs: Annotated Bibliography

Benhamou, P. Y. (2011). Improving diabetes management with electronic health records and patients' health records. *Diabetes & Metabolism*, 37(Suppl 4), S53-6.

doi:10.1016/S1262-3636(11)70966-1

The lack of patient engagement and clinical inertia both contribute to suboptimal diabetes care. However, both obstacles are amenable to informatics- and Internet-based interventions. The use of electronic medical records (EMRs) is now established as being useful for improving diabetes care. Intelligent records that integrate computerized decision-support systems are now able to recommend care protocols tailored to risk levels. Web-based personal health record (PHR) systems, shared with healthcare providers, could also provide added value by promoting self-management of the behaviours related to diabetes. These Web-based programmes include patients' access to EMRs, uploading of glucose monitoring results, a glucose diary, secure e-mail with providers, manual or automated feedback on blood glucose readings and other risk factors, an educational website, and an online diary for entering personal information on exercise, diet and medication. The integration of Web-based patients' systems into the EMR used by physicians is the next frontier. In addition, the input from "smartphones" that are able to provide real-time support to patients could contribute to the reorganization of diabetes care. Convincing data on HbA(1c) improvements with such systems are available for type 2 diabetes, but are still equivocal for type 1 diabetes. Obstacles include patients' compliance with the

technology, their ergonomic design and the need to reimburse providers for their care. Designing appropriate electronic tools and tailoring them to the conditions in France merits our attention.

Bourgeois, F. C., Mandl, K. D., Shaw, D., Flemming, D., & Nigrin, D. J. (2009). Mychildren's: integration of a personally controlled health record with a tethered patient portal for a pediatric and adolescent population. *AMIA Annual Symposium Proceedings, 2009*, 65-69.

Personally controlled health records (PCHRs) and patient portals are increasingly being offered by healthcare institutions, employers, insurance companies and commercial entities to allow patients access to their health information. Both applications offer unique services to provide patients with tools to manage their health. While PCHRs allow users ubiquitous, portable, patient controlled access to their health information, traditional patient portals provide provider-tethered applications allowing patients access, but not control of, certain healthcare information, as well as communication and administrative functions, such as secure messaging, appointment management and prescription refill requests, facilitating care at a specific healthcare facility. We describe our approach for the design, content creation, policy development, and implementation of MyChildren's, a unique web-based application leveraging the advantages of both a provider-tethered patient portal and a PCHR to allow patients and their guardians access to the functionality and convenience of a traditional patient portal, as well as the portability and flexibility of a PCHR.

Britto, M. T., & Wimberg, J. (2009). Pediatric personal health records: current trends and key challenges. *Pediatrics*, 123 Suppl 2, S97-9. doi:10.1542/peds.2008-1755I

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.

Burke, R. P., Rossi, A. F., Wilner, B. R., Hannan, R. L., Zabinsky, J. A., & White, J. A. (2010).

Transforming patient and family access to medical information: Utilisation patterns of a patient-accessible electronic health record. *Cardiology in the Young*, 20(5), 477-484. doi:10.1017/S1047951110000363

OBJECTIVE: The purpose of this study was to evaluate the utilisation of a web-based multimedia patient-accessible electronic health record, for patients with congenital cardiac disease. **PATIENTS AND METHODS:** This was a prospective analysis of patients undergoing congenital cardiac surgery at a single institution from 1 September, 2006 to 1 February, 2009. After meetings with hospital administration, physicians, nurses, and patients, we configured a subset of the cardiac program's web-based clinical electronic health record for patient and family access. The Electronic Health Record continuously measured frequency and time of logins, logins during and between hospitalisations, and page views by type (imaging versus textual data). **RESULTS:** Of the first 270 patients offered access to the system, 252 became users (93% adoption rate). System uptime was 99.9%, and no security breaches were reported. Users accessed the system more often while the patients were in hospital (67% of total

logins) than after discharge (33% of total logins). The maximum number of logins by a family was 440, and the minimum was 1. The average number of logins per family was 25. Imaging data were viewed significantly more frequently than textual data ($p < 0.001$). A total of 12 patients died during the study period and 11 members of their families continued to access their Electronic Health Records after the date of death.

CONCLUSIONS: A web-based Patient Accessible Electronic Health Record was designed for patients with congenital cardiac disease. The adoption rate was high, and utilisation patterns suggest that the Electronic Health Record could become a useful tool for health information exchange.

Chinn, M. D., & Fairlie, R. W. (2004). The determinants of the global digital divide: A cross-country analysis of computer and internet penetration. *Yale University Economic Growth Center Discussion Papers*, (881) Retrieved from http://www.econ.yale.edu/growth_pdf/cdp881.pdf

To identify the determinants of cross-country disparities in personal computer and Internet penetration, we examine a panel of 161 countries over the 1999-2001 period. Our candidate variables include economic variables (income per capita, years of schooling, illiteracy, trade openness), demographic variables (youth and aged dependency ratios, urbanization rate), infrastructure indicators (telephone density, electricity consumption), telecommunications pricing measures, and regulatory quality. With the exception of trade openness and the telecom pricing measures, these variables enter in as statistically significant in most specifications for computer use. A similar pattern holds true for Internet use, except that telephone density and aged dependency matter less. The global digital divide is mainly – but by no means entirely

– accounted for by income differentials. For computers, telephone density and regulatory quality are of second and third importance, while for the Internet, this ordering is reversed. The region-specific explanations for large disparities in computer and Internet penetration are generally very similar. Our results suggest that public investment in human capital, telecommunications infrastructure, and the regulatory infrastructure can mitigate the gap in PC and Internet use.

Chung, J., Berkowicz, D. A., Ho, B., Jernigan, M., & Chueh, H. (2011). Creating a place for caregivers in personal health: the iHealthSpace copilot program and diabetes care. *Journal of Diabetes Science and Technology*, 5(1), 39-46. Retrieved from <http://www.ncbi.nlm.nih.gov.ezp2.lib.umn.edu/pmc/articles/PMC3045238/>

BACKGROUND: As America's baby boom generation reaches retirement, the number of elders, and, in turn, the number of lay individuals who support them, will continue to increase. With the important services caregivers provide, it is critical that we recognize and provide assistance to the informal caregivers who play this important role in our society. The network of support provisioned by relatives, partners, friends, and neighbors suggests that the dyadic, unidirectional caregiver-care recipient relationship assumed by caregiver research so far and by resources deployed to assist caregivers may be insufficient to ascertain and meet the needs of the care community. METHODS: In this article, we describe the extension of a Web-based personal health record system, iHealthSpace, for explicitly and openly incorporating caregivers into the care community. RESULTS: Using this portal, a set of business rules was implemented to support the creation of custodial accounts. These business rules will be used to create modules that support diabetes care in an adult population. CONCLUSIONS: We

successfully extended an existing patient portal to accommodate the creation of custodial accounts. We will use this portal to assess the impact of custodial access in the care of older patients with diabetes.

Clarke, J. L., Meiris, D. C., & Nash, D. B. (2006). Electronic personal health records come of age. *American Journal of Medical Quality*, 21(3 Suppl), 5S-15S.

doi:10.1177/1062860606287642

The authors provide background information distinguishing a PHR, from EHR, and EMR. They describe consumer and provider issues that may prevent using a PHR. The authors then go onto proposing a solution - LifeSensor, which is a Web-based PHR that is highly protected and secured via encryption, distributed data storage, authorization, and authentication. It is patient centered and patient controlled, with utility for physicians to encourage their acceptance. Only the patient has the right to grant a clinician access to his or her PHR.

Collins, S. A., Vawdrey, D. K., Kukafka, R., & Kuperman, G. J. (2011). Policies for patient access to clinical data via PHRs: Current state and recommendations. *Journal of the American Medical Informatics Association*, 18 Suppl 1(Suppl 1), i2-7.

doi:10.1136/amiajnl-2011-000400

OBJECTIVE: Healthcare delivery organizations are increasingly using online personal health records (PHRs) to provide patients with direct access to their clinical information; however, there may be a lack of consistency in the data made available. We aimed to understand the general use and functionality of PHRs and the organizational policies and decision-making structures for making data available to

patients. MATERIALS AND METHODS: A cross-sectional survey was administered by telephone structured interview to 21 organizations to determine the types of data made available to patients through PHRs and the presence of explicit governance for PHR data release. Organizations were identified based on a review of the literature, PHR experts, and snowball sampling. Organizations that did not provide patients with electronic access to their data via a PHR were excluded. RESULTS: Interviews were conducted with 17 organizations for a response rate of 81%. Half of the organizations had explicit governance in the form of a written policy that outlined the data types made available to patients. Overall, 88% of the organizations used a committee structure for the decision-making process and included senior management and information services. All organizations sought input from clinicians. Discussion There was considerable variability in the types of clinical data and the time frame for releasing these data to patients. Variability in data release policies may have implications for PHR use and adoption. CONCLUSIONS: Future policy activities, such as requirement specification for the latter stages of Meaningful Use, should be leveraged as an opportunity to encourage standardization of functionality and broad deployment of PHRs.

Copeland, W., & Keckley, P. (2008). *Deloitte 2008 Survey of Healthcare Consumers Executive Summary*. Retrieved April 22, 2011, from http://www.deloitte.com/assets/Dcom-UnitedStates/Local%20Assets/Documents/us_chs_ConsumerSurveyExecutiveSummary_200208.pdf

This research study by the Deloitte Center for Health Solutions, part of Deloitte LLP, provides an important and timely perspective on health care consumerism. It features a comprehensive assessment of consumers' behaviors, attitudes and unmet needs related to health, health care and health insurance. It also points to six discrete segments of the overall consumer market, providing a profile of their key characteristics and differences.

Curtis, J., Cheng, S., Rose, K., & Tsai, O. (2011). Promoting adoption, usability, and research for personal health records in Canada: The MyChart experience. *Healthcare Management Forum* 24(3), 149-154.

Sunnybrook's MyChart Personal Health Record (PHR) represents a direct extension of the hospital's electronic health record and an innovative form of healthcare record that promises to change the way patients and providers access and manage the information required to participate in their care. Early attempts at the development of PHR features have evolved into a set of emergent best practices that should directly inform the ongoing development of the MyChart platform and should be complemented with a research agenda that supports evidence-based analysis and design considerations affecting clinical efficacy, administrative efficiency, and value generation for all PHR stakeholders.

Do, N. V., Barnhill, R., Heermann-Do, K. A., Salzman, K. L., & Gimbel, R. W. (2011). The military health system's personal health record pilot with Microsoft HealthVault and Google Health. *Journal of the American Medical Informatics Association*, 18(2), 118-124. doi:10.1136/jamia.2010.004671

OBJECTIVE: To design, build, implement, and evaluate a personal health record (PHR), tethered to the Military Health System, that leverages Microsoft(R) HealthVault and Google(R) Health infrastructure based on user preference. MATERIALS AND METHODS: A pilot project was conducted in 2008-2009 at Madigan Army Medical Center in Tacoma, Washington. Our PHR was architected to a flexible platform that incorporated standards-based models of Continuity of Document and Continuity of Care Record to map Department of Defense-sourced health data, via a secure Veterans Administration data broker, to Microsoft(R) HealthVault and Google(R) Health based on user preference. The project design and implementation were guided by provider and patient advisory panels with formal user evaluation. RESULTS: The pilot project included 250 beneficiary users. Approximately 73.2% of users were < 65 years of age, and 38.4% were female. Of the users, 169 (67.6%) selected Microsoft(R) HealthVault, and 81 (32.4%) selected Google(R) Health as their PHR of preference. Sample evaluation of users reflected 100% (n = 60) satisfied with convenience of record access and 91.7% (n = 55) satisfied with overall functionality of PHR. DISCUSSION: 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. CONCLUSION: Currently PHRs are being viewed as empowering tools for patient activation. Design and implementation issues (eg, technical, organizational, information security) are substantial and must be thoughtfully approached. Adopting standards into design can enhance the national goal of portability and interoperability.

Gamble, K. H. (2009). Is it registering? Patient portals, part II. *Healthcare Informatics*, 26(5), 24, 26, 28. Retrieved from <http://www.healthcare-informatics.com/article/it-registering-patient-portals-part-ii-see-financial-department-part-i>

While the trend has been slowed by the economy, portal adoption is growing. CIOs are deploying portals that enable patients to access lab results, request or cancel appointments and get discharge information. Some portals enable patients to communicate directly with physicians and view their records. While some portals integrate with EMRs (including lab and pharmacy), others sit on top. Many patients--and CIOs--still have concerns regarding privacy and security. Some experts believe portals will integrate further with hospital information systems in the future, and will include functions like e-prescribing.

Grossman, J. M., Zayas-Caban, T., & Kemper, N. (2009). Information gap: Can health insurer personal health records meet patients' and physicians' needs? *Health Affairs (Project Hope)*, 28(2), 377-389. doi:10.1377/hlthaff.28.2.377

Personal health records (PHRs), centralized places for people to electronically store and organize their health information, can benefit both patients and doctors. This qualitative study of health insurers' PHRs for enrollees reveals potential benefits and challenges. Insurers' ability to put claims-based data into the PHR offers an advantage. However, consumers are concerned about sharing personal health information with insurers and about Internet security. Physicians question (1) the validity of claims data in making treatment decisions and (2) whether accessing these PHRs is worth the disruptions to their workflow. This paper offers possible solutions that may lead to more widespread adoption of insurer PHRs.

Haggstrom, D. A., Saleem, J. J., Russ, A. L., Jones, J., Russell, S. A., & Chumbler, N. R. (2011).

Lessons learned from usability testing of the VA's personal health record. *Journal of the American Medical Informatics Association*, 18(Suppl 1), i13-7. doi:10.1136/amiajnl-2010-000082

In order to create user-centered design information to guide the development of personal health records (PHRs), 24 patients participated in usability assessments of VA's MyHealtheVet program. 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. Twenty-five percent of users successfully completed registration. Individuals preferred prescription numbers over names, sometimes due to privacy concerns. Only efficiency in prescription refills was significantly better than target values. Users wanted to print their information to share with their doctors, and questioned the value of MyHealtheVet search functions over existing online health information. In summary, PHR registration must balance simplicity and security, usability tests guide how PHRs can tailor functions to individual preferences, PHRs add value to users' data by making information more accessible and understandable, and healthcare organizations should build trust for PHR health content.

Kaiser Permanente News Center. (2007). *Kaiser Permanente connects teens online with their doctors*. Retrieved April 29, 2012, from

<http://xnet.kp.org/newscenter/pressreleases/co/2007/062607emailteens.html>

More and more people are using the Internet to find health information and many are clamoring for the ability to connect with their physicians by email. Yet, the medical

industry is slow to meet this demand according to the latest Harris Interactive poll. Now, Kaiser Permanente Colorado (KP CO) has extended its patient-physician email system and online medical record to a population ready to be wired to do their "health homework" online — teens.

Keoh, S. L., Asim, M., Kumar, S. S., & Lenoir, P. J. (2011). Secure Spontaneous Emergency Access to Personal Health Record. Paper presented at the *Proceedings of the 3rd International Workshop on Security and Privacy in Spontaneous Interaction and Mobile Phone use in Conjunction with Pervasive 2011*, San Francisco, CA, USA. Retrieved from <http://syeloong.co.uk/Documents/iwssi-spmu2011-01.pdf>

We propose a system which enables access to the user's Personal Health Record (PHR) in the event of emergency. The access typically occurs in an ad-hoc and spontaneous manner and the user is usually unconscious, hence rendering the unavailability of the user's password to access the PHR. The proposed system includes a smart card carried by the user at all time and it is personalized with a pseudo secret, an URL to the PHR Server, a secret key shared with the PHR Server and a number of redemption tokens generated using a hash chain. In each emergency session, a one-time use redemption token is issued by the smart card, allowing the emergency doctor to retrieve the user's PHR upon successful authentication of his credentials and validation of the redemption token. The server returns the PHR encrypted with a one-time session key which can only be decrypted by the emergency doctor. The devised interaction protocol to facilitate emergency access to the user's PHR is secure and efficient.

Reti, S. R., Feldman, H. J., Ross, S. E., & Safran, C. (2010). Improving personal health records for patient-centered care. *Journal of the American Medical Informatics Association*, 17(2), 192-195. doi:10.1136/jamia.2009.000927

OBJECTIVE: To assess the patient-centeredness of personal health records (PHR) and offer recommendations for best practice guidelines. DESIGN: Semi-structured interviews were conducted in seven large early PHR adopter organizations in 2007. Organizations were purposively selected to represent a variety of US settings, including medium and large hospitals, ambulatory care facilities, insurers and health plans, government departments, and commercial sectors. MEASUREMENTS: 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; (8) coordination of care. Within this framework we used evidence for patient preferences (where it exists) to compare existing PHR policies, and propose a best practice model. RESULTS: 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. CONCLUSION: Findings suggest patient-centeredness for personal health records can be improved, and recommendations are made for best practice guidelines.

Weitzman, E. R., Kaci, L., & Mandl, K. D. (2010). Sharing medical data for health research: The early personal health record experience. *Journal of Medical Internet Research*,

12(2), e14. doi:10.2196/jmir.1356

BACKGROUND: Engaging consumers in sharing information from personally controlled health records (PCHRs) for health research may promote goals of improving care and advancing public health consistent with the federal Health Information Technology for Economic and Clinical Health (HITECH) Act. Understanding consumer willingness to share data is critical to advancing this model. **OBJECTIVE:** The objective was to characterize consumer willingness to share PCHR data for health research and the conditions and contexts bearing on willingness to share. **METHODS:** A mixed method approach integrating survey and narrative data was used. Survey data were collected about attitudes toward sharing PCHR information for health research from early adopters (n = 151) of a live PCHR populated with medical records and self-reported behavioral and social data. Data were analyzed using descriptive statistics and logistic regression to characterize willingness, conditions for sharing, and variations by sociodemographic factors. Narrative data were collected through semistructured focus group and one-on-one interviews with a separate sample of community members (n = 30) following exposure to PCHR demonstrations. Two independent analysts coded narrative data for major and minor themes using a shared rubric of a priori defined codes and an iterative inductive process. Findings were triangulated with survey results to identify patterns. **RESULTS:** Of PHCR users, 138 out of 151 (91%) were willing to share medical information for health research with 89 (59%) favoring an opt-in sharing model. Willingness to share was conditioned by anonymity, research use, engagement with a trusted intermediary, transparency around PCHR access and use, and payment. Consumer-determined restrictions on content and timing of sharing

may be prerequisites to sharing. 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 (unadjusted odds ratio [OR] = 2.89, 95% confidence interval [CI] 1.10 - 7.62, P = .03). Participants over age 50 were less likely than younger participants to report that payment would increase willingness to share (unadjusted OR = 0.94, 95% CI 0.91 - 0.96, P < .001). Students were more likely than nonstudents to report that payment would increase their willingness to share (unadjusted OR 9.62, 95% CI 3.44 - 26.87, P < .001). Experiencing a public health emergency may increase willingness to share especially among persons over 50 (unadjusted OR 1.03, 95% CI 1.01 - 1.05, P = .02); however, students were less likely than non-students to report this attitude (unadjusted OR 0.13, 95% CI 0.05 - 0.36, P < .001). 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 (unadjusted OR 0.61, 95% CI 0.38 - 0.97, P = .04). CONCLUSIONS: 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.

Wiljer, D., Urowitz, S., Apatu, E., DeLenardo, C., Eysenbach, G., Harth, T., . . . Canadian

Committee for Patient Accessible Health Records. (2008). Patient accessible electronic

health records: exploring recommendations for successful implementation strategies.

Journal of Medical Internet Research, 10(4), e34. doi:10.2196/jmir.1061

BACKGROUND: Providing patients with access to their electronic health records offers great promise to improve patient health and satisfaction with their care, as well to improve professional and organizational approaches to health care. Although many benefits have been identified, there are many questions about best practices for the implementation of patient accessible Electronic Health Records (EHRs). **OBJECTIVES:** To develop recommendations to assist health care organizations in providing patients with access to EHRs in a meaningful, responsible, and responsive manner. **METHODS:** A Patient Accessible Electronic Health Record (PAEHR) Workshop was held with nationally and internationally renowned experts to explore issues related to providing patient access to the EHR and managing institutional change. **RESULTS:** The PAEHR Workshop was attended by 45 participants who discussed recommendations for the implementation of patient accessible EHRs. Recommendations were discussed under four subject domains: (1) providing patient access to the EHR, (2) maintaining privacy and confidentiality related to the PAEHR, (3) patient education and navigation of the PAEHR, and (4) strategies for managing institutional change. The discussion focused on the need for national infrastructure, clear definitions for privacy, security and confidentiality, flexible, interoperable solutions, and patient and professional education. In addition, there was a strong call for research into all domains of patient accessible EHRs to ensure the adoption of evidence-based practices. **CONCLUSIONS:** Patient access to personal health information is a fundamental issue for patient engagement and empowerment. Health care professionals and organizations should

consider the potential benefits and risks of patient access when developing EHR strategies. Flexible, standardized, and interoperable solutions must be integrated with outcomes-based research to activate effectively patients as partners in their health care.

Yamin, C. K., Emani, S., Williams, D. H., Lipsitz, S. R., Karson, A. S., Wald, J. S., & Bates, D. W. (2011). The digital divide in adoption and use of a personal health record. *Archives of Internal Medicine*, 171(6), 568-574.

BACKGROUND: Personal health records (PHRs) offer the potential to improve the patient experience and the quality of patient care. However, the "digital divide," the population-level gap in Internet and computer access, may prevent certain groups from accessing the PHR. **METHODS:** We conducted a cross-sectional analysis of a PHR within a northeastern health system. We compared adopters (ie, those activating a PHR account online) with nonadopters (ie, those who see a physician offering the PHR but do not activate an account). We further categorized adopters by intensity of PHR use, measured by number of log-ins and number of messages sent to physicians' practices. **RESULTS:** As of September 30, 2009, among 75,056 patients, 43% had adopted the PHR since 2002. Blacks and Hispanics were less likely to adopt the PHR compared with whites (odds ratio [OR], 0.50; 95% confidence interval [CI], 0.45-0.55; and 0.64; 0.57-0.73, respectively), and those with lower annual income were less likely to adopt the PHR than were those with higher income. Compared with nonadopters, adopters were more likely to have more than 2 comorbidities (OR, 1.27; 95% CI, 1.17-1.30). Use of an aggressive marketing strategy for PHR enrollment increased adoption nearly 3-fold (OR, 2.92; 95% CI, 1.58-5.40). Intensity of use was best predicted by

increasing number of comorbidities, followed by race/ethnicity (whites more than blacks and Hispanics) and insurance status. We found no association between income and log-in frequency or secure messages sent. CONCLUSIONS: 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.

Attitudes-Consumer: Annotated Bibliography

Atkinson, N. L., Massett, H. A., Mylks, C., Hanna, B., Deering, M. J., & Hesse, B. W. (2007).

User-centered research on breast cancer patient needs and preferences of an Internet-based clinical trial matching system. *Journal of Medical Internet Research*, 9(2), e13.
doi:10.2196/jmir.9.2.e13

BACKGROUND: Internet-based clinical trial matching systems have the potential to streamline the search process for women with breast cancer seeking alternative treatments. A prototype system was developed to leverage the capabilities of a personal health record system for the purpose of identifying clinical trials. **OBJECTIVE:** This study examines how breast cancer patients perceive and interact with a preliminary version of an Internet-based clinical trial matching system, while taking into account the demands of diagnosis and treatment decision making. **METHODS:** Breast cancer patients participated in small group discussions and interacted with the prototype website in a two-phase qualitative research process. The first phase explored the experience of breast cancer patients (n = 8) with treatment decision making, initial responses to the idea of Internet-based clinical trial matching systems, and reactions to the prototype site. In the second phase, a different set of breast cancer patients (n = 7) reviewed revised website content and presentation and participated in a usability test in which they registered on the system and completed a personal health record to set up the matching process. **RESULTS:** Participants were initially skeptical of the prototype system because it emphasized registration, had a complicated registration process, and asked for complex medical information. Changing content and attending to usability guidelines improved the experience for women in the

second phase of the research and enabled the identification of functionality and content issues, such as lack of clear information and directions on how to use the system. CONCLUSIONS: This study showed that women felt favorably about the idea of using the Internet to search for clinical trials but that such a system needed to meet their expectations for credibility and privacy and be sensitive to their situation. Developers can meet these expectations by conforming to established usability guidelines and testing improvements with breast cancer patients. Future research is needed to verify these findings and to continue to improve systems of this nature.

Berry, J. G., Goldmann, D. A., Mandl, K. D., Putney, H., Helm, D., O'Brien, J., . . . Weinick, R. M. (2011). Health information management and perceptions of the quality of care for children with tracheotomy: A qualitative study. *BMC Health Services Research, 11*, 117. doi:10.1186/1472-6963-11-117

BACKGROUND: Children with tracheotomy receive health care from an array of providers within various hospital and community health system sectors. Previous studies have highlighted substandard health information exchange between families and these sectors. The aim of this study was to investigate the perceptions and experiences of parents and providers with regard to health information management, care plan development and coordination for children with tracheotomy, and strategies to improve health information management for these children. METHODS: Individual and group interviews were performed with eight parents and fifteen healthcare (primary and specialty care, nursing, therapist, equipment) providers of children with tracheotomy. The primary tracheotomy-associated diagnoses for the children were neuromuscular impairment (n = 3), airway anomaly (n = 2) and chronic lung disease

(n = 3). Two independent reviewers conducted deep reading and line-by-line coding of all transcribed interviews to discover themes associated with the objectives. RESULTS: Children with tracheotomy in this study had healthcare providers with poorly defined roles and responsibilities who did not actively communicate with one another. Providers were often unsure where to find documentation relating to a child's tracheotomy equipment settings and home nursing orders, and perceived that these situations contributed to medical errors and delayed equipment needs. Parents created a home record that was shared with multiple providers to track the care that their children received but many considered this a burden better suited to providers. Providers benefited from the parent records, but questioned their accuracy regarding critical tracheotomy care plan information such as ventilator settings. Parents and providers endorsed potential improvement in this environment such as a comprehensive internet-based health record that could be shared among parents and providers, and between various clinical sites. CONCLUSIONS: Participants described disorganized tracheotomy care and health information mismanagement that could help guide future investigations into the impact of improved health information systems for children with tracheotomy. Strategies with the potential to improve tracheotomy care delivery could include defined roles and responsibilities for tracheotomy providers, and improved organization and parent support for maintenance of home-based tracheotomy records with web-based software applications, personal health record platforms and health record data authentication techniques.

Bonney, W. (2011). The use of biometrics in the Personal Health Record (PHR). *Studies in Health Technology and Informatics*, 164, 110-116.

The emergence of the Personal Health Record (PHR) has made individual health information more readily accessible to a wide range of users including patients, consumers, practitioners, and healthcare providers. However, increased accessibility of PHR threatens the confidentiality, privacy, and security of personalized health information. Therefore, a need for robust and reliable forms of authentication is of prime concern. The concept of biometric authentication is now highly visible to healthcare providers as a technology to prevent unauthorized access to individual health information. Implementing biometric authentication mechanisms to protect PHR facilitates access control and secure exchange of health information. In this paper, a literature review is used to explore the key benefits, technical barriers, challenges, and ethical implications for using biometric authentication in PHR.

Brennan, P. F., Downs, S., & Casper, G. (2010). Project HealthDesign: Rethinking the power and potential of personal health records. *Journal of Biomedical Informatics*, 43(5 Suppl), S3-5. doi:10.1016/j.jbi.2010.09.001

Project HealthDesign, a multi-year, multi-site project sponsored by the Robert Wood Johnson Foundation with additional support from the California HealthCare Foundation, is designed to stimulate innovation in personal health records (PHRs). Project HealthDesign teams employed user-centered design processes to create designs and prototypes of computer-based applications to support and enhance human health for a wide range of patients, from children with chronic health conditions to elders transitioning from hospital to home. A program design philosophy

encouraged designers to envision PHRs as a suite of personal health information management tools, or applications, separate from, but drawing upon, personal health data from a variety of sources. In addition to information contained in one's medical record, these personal health data included patient-supplied clinical parameters such as blood glucose and daily weights; as well as patient-generated observations of daily living (ODLs) - the unique, idiosyncratic cues, such as sleep adequacy or confidence in self care, that inform patients about their abilities to manage health challenges and take healthy action. A common technical platform provided infrastructure services such as data standards and identity-management protocols, and helped to demonstrate a scalable, efficient approach to user-centered design of personal health information management systems. The program's ethical, legal and social issues consultancy identified challenges to acceleration of action-focused PHRs: personal control of privacy choices, management of privacy in home conditions, and rebalancing power structures in shared decision making.

Britto, M. T., Jimison, H. B., Munafo, J. K., Wissman, J., Rogers, M. L., & Hersh, W. (2009).

Usability testing finds problems for novice users of pediatric portals. *Journal of the American Medical Informatics Association*, 16(5), 660-669. doi:10.1197/jamia.M3154

OBJECTIVE: Patient portals may improve pediatric chronic disease outcomes, but few have been rigorously evaluated for usability by parents. Using scenario-based testing with think-aloud protocols, we evaluated the usability of portals for parents of children with cystic fibrosis, diabetes or arthritis. DESIGN Sixteen parents used a prototype and test data to complete 14 tasks followed by a validated satisfaction questionnaire. Three iterations of the prototype were used. MEASUREMENTS: During the usability testing,

we measured the time it took participants to complete or give up on each task. Sessions were videotaped and content-analyzed for common themes. Following testing, participants completed the Computer Usability Satisfaction Questionnaire which measured their opinions on the efficiency of the system, its ease of use, and the likeability of the system interface. A 7-point Likert scale was used, with seven indicating the highest possible satisfaction. RESULTS: Mean task completion times ranged from 73 (+/- 61) seconds to locate a document to 431 (+/- 286) seconds to graph laboratory results. Tasks such as graphing, location of data, requesting access, and data interpretation were challenging. Satisfaction was greatest for interface pleasantness (5.9 +/- 0.7) and likeability (5.8 +/- 0.6) and lowest for error messages (2.3 +/- 1.2) and clarity of information (4.2 +/- 1.4). Overall mean satisfaction scores improved between iteration one and three. CONCLUSIONS: Despite parental involvement and prior heuristic testing, scenario-based testing demonstrated difficulties in navigation, medical language complexity, error recovery, and provider-based organizational schema. While such usability testing can be expensive, the current study demonstrates that it can assist in making healthcare system interfaces for laypersons more user-friendly and potentially more functional for patients and their families.

Brownstein, C. A., & Wicks, P. (2010). The potential research impact of patient reported outcomes on osteogenesis imperfecta. *Clinical Orthopaedics and Related Research*, 468(10), 2581-2585. doi:10.1007/s11999-010-1373-x

BACKGROUND: Osteogenesis imperfecta (OI) is an inherited connective tissue disorder with many phenotypic presentations ranging from mild to severe. It is often called

"brittle bone disease." Treatment consists of physical therapy, surgical interventions, medications and, in some cases, experimental therapies. Because treatment is not standardized and is often experimental, information on the success of different methods is usually not available or well documented. QUESTIONS/PURPOSES: We therefore asked if social networking can make OI patients' lives better. How would a bone disorder community work? Is it possible for patients to know how well they are doing in comparison to others like them, and if they are getting the most successful treatment for their disease? METHODS: An evaluation of how PatientsLikeMe(R), a personal research and social networking website and database for patients with life changing illnesses, can aid in improving patient outcomes through the anonymous sharing of medical information. RESULTS: PatientsLikeMe(R) could help patients answer the question, "Given my condition, what is the best outcome I could hope to achieve, and how do I get there?" Participants could record their real-time day-to-day progress in achieving their treatment goals, such as preventing fractures, and share that with the community to help patients, caregivers, researchers and industry learn more about OI. CONCLUSIONS: Social networking can change the lives of Osteogenesis Imperfecta patients for the better, and make them a part of the treatment discovery process. Here we present a possible OI online community and demonstrate its potential utility for patients and medical professionals alike.

Burke, R. P., Rossi, A. F., Wilner, B. R., Hannan, R. L., Zabinsky, J. A., & White, J. A. (2010).

Transforming patient and family access to medical information: Utilisation patterns of a patient-accessible electronic health record. *Cardiology in the Young*, 20(5), 477-484.

doi:10.1017/S1047951110000363

OBJECTIVE: The purpose of this study was to evaluate the utilisation of a web-based multimedia patient-accessible electronic health record, for patients with congenital cardiac disease. **PATIENTS AND METHODS:** This was a prospective analysis of patients undergoing congenital cardiac surgery at a single institution from 1 September, 2006 to 1 February, 2009. After meetings with hospital administration, physicians, nurses, and patients, we configured a subset of the cardiac program's web-based clinical electronic health record for patient and family access. The Electronic Health Record continuously measured frequency and time of logins, logins during and between hospitalisations, and page views by type (imaging versus textual data). **RESULTS:** Of the first 270 patients offered access to the system, 252 became users (93% adoption rate). System uptime was 99.9%, and no security breaches were reported. Users accessed the system more often while the patients were in hospital (67% of total logins) than after discharge (33% of total logins). The maximum number of logins by a family was 440, and the minimum was 1. The average number of logins per family was 25. Imaging data were viewed significantly more frequently than textual data ($p < 0.001$). A total of 12 patients died during the study period and 11 members of their families continued to access their Electronic Health Records after the date of death. **CONCLUSIONS:** A web-based Patient Accessible Electronic Health Record was designed for patients with congenital cardiac disease. The adoption rate was high, and utilisation patterns suggest that the Electronic Health Record could become a useful tool for health information exchange.

Caligtan, C. A., & Dykes, P. C. (2011). Electronic health records and personal health records.

Seminars in Oncology Nursing, 27(3), 218-228. doi:10.1016/j.soncn.2011.04.007;

10.1016/j.soncn.2011.04.007

OBJECTIVES: To provide an overview of electronic personal health information technology. DATA SOURCES: Peer reviewed research studies, review articles, and web resources. CONCLUSION: As technology develops and electronic health records become more common, patients and clinicians are working toward a safer, more personal form of health care delivery. IMPLICATIONS FOR NURSING PRACTICE: Improving access and input to personal health information is still in its infancy, but with government funding, development of patient health records will continue to grow. Patients are the consumers of health care and are witness to the paradigm shift of access to health information and changes in information communication technology (ICT). For the oncology nurse, the transformation of health care and ICT will require nurses to educate patients and family members on available online resources for self management and health promotion.

Clarke, J. L., Meiris, D. C., & Nash, D. B. (2006). Electronic personal health records come of age. *American Journal of Medical Quality*, 21(3 Suppl), 5S-15S.

doi:10.1177/1062860606287642 – The authors provide background information distinguishing a PHR, from EHR, and EMR. They describe consumer and provider issues that may prevent using a PHR. The authors then go onto proposing a solution - LifeSensor, which is a Web-based PHR that is highly protected and secured via encryption, distributed data storage, authorization, and authentication. It is patient centered and patient controlled, with utility for physicians to encourage their acceptance. Only the patient has the right to grant a clinician access to his or her PHR.

Cudney, S., Weinert, C., & Kinion, E. (2011). Forging partnerships between rural women with chronic conditions and their health care providers. *Journal of Holistic Nursing : Official Journal of the American Holistic Nurses' Association*, 29(1), 53-60.

doi:10.1177/0898010110373656

Successful adaptation to chronic illness is enhanced by active client-health care provider partnerships. The purposes of this article are to (a) examine the health care partnership needs of western rural women with chronic illness who participated in a computer-based support and education project, (b) describe how the role of the women in the partnership can be maximized by the use of a personal health record and improving health literacy, and (c) discuss ways health care providers can enhance their role in the partnership by careful listening and creating environments conducive to forging productive client-provider partnerships.

Do, N. V., Barnhill, R., Heermann-Do, K. A., Salzman, K. L., & Gimbel, R. W. (2011). The military health system's personal health record pilot with Microsoft HealthVault and Google Health. *Journal of the American Medical Informatics Association*, 18(2), 118-124.

doi:10.1136/jamia.2010.004671

OBJECTIVE: To design, build, implement, and evaluate a personal health record (PHR), tethered to the Military Health System, that leverages Microsoft(R) HealthVault and Google(R) Health infrastructure based on user preference. MATERIALS AND METHODS: A pilot project was conducted in 2008-2009 at Madigan Army Medical Center in Tacoma, Washington. Our PHR was architected to a flexible platform that incorporated standards-based models of Continuity of Document and Continuity of Care Record to map Department of Defense-sourced health data, via a secure Veterans

Administration data broker, to Microsoft(R) HealthVault and Google(R) Health based on user preference. The project design and implementation were guided by provider and patient advisory panels with formal user evaluation. RESULTS: The pilot project included 250 beneficiary users. Approximately 73.2% of users were < 65 years of age, and 38.4% were female. Of the users, 169 (67.6%) selected Microsoft(R) HealthVault, and 81 (32.4%) selected Google(R) Health as their PHR of preference. Sample evaluation of users reflected 100% (n = 60) satisfied with convenience of record access and 91.7% (n = 55) satisfied with overall functionality of PHR. DISCUSSION: 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. CONCLUSION: Currently PHRs are being viewed as empowering tools for patient activation. Design and implementation issues (eg, technical, organizational, information security) are substantial and must be thoughtfully approached. Adopting standards into design can enhance the national goal of portability and interoperability.

Fricton, J. R., & Davies, D. (2008). Personal health records to improve health information exchange and patient safety. In K. Henriksen, J. B. Battles, M. A. Keyes & M. L. Grady (Eds.), *Advances in Patient Safety: New Directions and Alternative Approaches (Vol. 4: Technology and Medication Safety)* (). Rockville (MD): Agency for Healthcare Research and Quality. Retrieved from

http://www.ahrq.gov/downloads/pub/advances2/vol4/advances-fricton_21.pdf

The personal health record (PHR) is proposed as an innovative solution to the problems of fragmented communication and lack of interoperability among diverse

electronic medical record (EMR) systems. It provides a single source (the patient's PHR) for authentication and remote access of the health information data from all EMR systems. A voluntary survey was offered to selected patients, caregivers, and health providers of the Willmar, MN, PHR project to determine if a PHR was useful to these stakeholders, and if so, what aspects of a PHR would be most helpful in caring for patients. The survey responses revealed nearly universal interest by both patients and health providers in using the PHR regularly for accessing and exchanging health information, including medication and medical history reconciliation and patient education. The highest utilization would result from a community-based PHR implementation that was owned and controlled by the consumer and was portable among providers, plans, and employers.

Grossman, J. M., Zayas-Caban, T., & Kemper, N. (2009). Information gap: Can health insurer personal health records meet patients' and physicians' needs? *Health Affairs (Project Hope)*, 28(2), 377-389. doi:10.1377/hlthaff.28.2.377

Personal health records (PHRs), centralized places for people to electronically store and organize their health information, can benefit both patients and doctors. This qualitative study of health insurers' PHRs for enrollees reveals potential benefits and challenges. Insurers' ability to put claims-based data into the PHR offers an advantage. However, consumers are concerned about sharing personal health information with insurers and about Internet security. Physicians question (1) the validity of claims data in making treatment decisions and (2) whether accessing these PHRs is worth the disruptions to their workflow. This paper offers possible solutions that may lead to more widespread adoption of insurer PHRs.

Haggstrom, D. A., Saleem, J. J., Russ, A. L., Jones, J., Russell, S. A., & Chumbler, N. R. (2011).

Lessons learned from usability testing of the VA's personal health record. *Journal of the American Medical Informatics Association*, 18 Suppl 1, i13-7. doi:10.1136/amiajnl-2010-000082

In order to create user-centered design information to guide the development of personal health records (PHRs), 24 patients participated in usability assessments of VA's MyHealtheVet program. 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. Twenty-five percent of users successfully completed registration. Individuals preferred prescription numbers over names, sometimes due to privacy concerns. Only efficiency in prescription refills was significantly better than target values. Users wanted to print their information to share with their doctors, and questioned the value of MyHealtheVet search functions over existing online health information. In summary, PHR registration must balance simplicity and security, usability tests guide how PHRs can tailor functions to individual preferences, PHRs add value to users' data by making information more accessible and understandable, and healthcare organizations should build trust for PHR health content.

Hargreaves, J. S. (2010). Will electronic personal health records benefit providers and patients in rural America? *Telemedicine Journal and e-Health*, 16(2), 167-176. doi:10.1089/tmj.2009.0063

PURPOSE: The objective of this study was to educate stakeholders (e.g., providers, patients, insurers, government) in the healthcare industry about electronic personal

health records (PHRs) and their potential application in rural America. METHODS: Extensive research was performed on PHRs through standard literature search, product demonstrations, educational webinars, and fact finding via news releases. RESULTS: Various stakeholders are eager to transform the healthcare industry into the digital age like other industries (i.e., banking, retail). Despite low adoption of PHRs in 2008 (2.7% of U.S. adults), patients are interested in secure messaging and eVisits with their physicians, online appointment scheduling and reminders, and online access to their laboratory and radiology results. Federal agencies (e.g., Health and Human Services, Department of Defense, Veterans Affairs [VA]), popular information technology (IT) vendors (e.g., Google, Microsoft), and large insurers (e.g., Aetna) have energized the industry through pilot programs and new product announcements. 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. CONCLUSIONS: 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.

Hess, R., Bryce, C. L., Paone, S., Fischer, G., McTigue, K. M., Olshansky, E., . . . Siminerio, L. (2007). Exploring challenges and potentials of personal health records in diabetes self-management: implementation and initial assessment. *Telemedicine Journal and e-Health : The Official Journal of the American Telemedicine Association*, 13(5), 509-517.

doi:10.1089/tmj.2006.0089

The University of Pittsburgh Medical Center (UPMC) has implemented a personal health record grounded in the Chronic Care Model, UPMC HealthTrak, to assist patients with diabetes self-management. UPMC HealthTrak is based in the physician office and connects the patient, physician, and electronic medical record (EMR). Its functionalities include secure, electronic communication with the physician's office, along with preventive healthcare reminders, and disease-specific tools and information. In this paper, we describe challenges to office-based implementation of and initial patient reaction to the technology in the context of diabetes care. UPMC has deployed a secure Web-based patient portal, UPMC HealthTrak. We implemented UPMC HealthTrak in the ambulatory setting and assessed its impact on patient-practice communication. We conducted 10 90-minute focus groups (five pre- and five postimplementation) to assess patient reaction to UPMC HealthTrak. Focus groups were analyzed using grounded theory techniques. During the period September 2004-January 2007, there was no significant change in number of patient encounters or telephone calls received in our office, but the number of HealthTrak messages increased. Our 39 pre- and postimplementation focus group participants felt that the system would enhance communication with the office, and that the reminder system would be helpful. They also liked having access to laboratory tests remotely. They were frustrated when tests were not released and messages not answered. A Web-based patient portal can be integrated into a clinical office, although patients may not quickly change communication patterns. Patients are responsive to technology. Future

work should focus on diabetes-related outcomes assessment and intensifying interventions.

Hoerbst, A., Kohl, C. D., Knaup, P., & Ammenwerth, E. (2010). Attitudes and behaviors related to the introduction of electronic health records among Austrian and German citizens. *International Journal of Medical Informatics*, 79(2), 81-89.

doi:10.1016/j.ijmedinf.2009.11.002

BACKGROUND: Acceptance by citizens seems to be crucial for the future success of an electronic health record (EHR) in Germany and Austria. We analyzed citizens' knowledge and expectations about the concept and contents of an EHR. We also addressed possible fears and barriers, and we investigated desired EHR functionalities relevant to citizens in the Austrian and German population. METHODS: Standardized interviews of a convenience sample of 203 Austrian and 293 German citizens recruited in two metropolises. RESULTS: Up to three-quarter of the interviewed citizens already collect and store medical documents at home, mostly in paper-based form. No respondents had already used an Internet-based personal health record. Between 80% and 90% of respondents were supportive of the idea of an electronic exchange of health-related data between health care providers as core functionality of an EHR. However, many respondents formulated concerns with regard to data protection and data security within an EHR. The EHR functionalities most supported by respondents included the electronic vaccination record, online information on doctors and hospitals, and the administration of appointments and reminders. CONCLUSION: The results indicate a generally positive attitude towards the EHR. However, the study

shows that data protection is an issue for many citizens, and that despite strong media discussion, there are information deficits with regard to the national EHR initiatives.

Kaelber, D. C., Jha, A. K., Johnston, D., Middleton, B., & Bates, D. W. (2008). A research agenda for personal health records (PHRs). *Journal of the American Medical Informatics Association*, 15(6), 729-736. doi:10.1197/jamia.M2547

Patients, policymakers, providers, payers, employers, and others have increasing interest in using personal health records (PHRs) to improve healthcare costs, quality, and efficiency. While organizations now invest millions of dollars in PHRs, the best PHR architectures, value propositions, and descriptions are not universally agreed upon. Despite widespread interest and activity, little PHR research has been done to date, and targeted research investment in PHRs appears inadequate. The authors reviewed the existing PHR specific literature (100 articles) and divided the articles into seven categories, of which four in particular--evaluation of PHR functions, adoption and attitudes of healthcare providers and patients towards PHRs, PHR related privacy and security, and PHR architecture--present important research opportunities. We also briefly discuss other research related to PHRs, PHR research funding sources, and PHR business models. We believe that additional PHR research can increase the likelihood that future PHR system deployments will beneficially impact healthcare costs, quality, and efficiency.

Kelso, L., & Walker, R. (2009). The consumer view of PHRs. Observational study finds most value PHRs, but issues remain. *Journal of AHIMA / American Health Information Management Association*, 80(10), 56-7, 59.

In 2008, an observational study attempted to determine the likelihood that people would complete a PHR. It also sought to find the level of effort people believe they would make to create an accurate PHR and determine how people thought they would use one. AHIMA used a paper form for the PHR in this study. Fifty-one percent said they were very or somewhat likely to complete a PHR for themselves or someone else; 22% already had a PHR.

Lowes, R. (2006). Personal health records: What's the status now? *Medical Economics*, 83(4), TCP13-4, TCP16.

Consumer oriented article describing the applicability of a PHR to various consumer situations.

Markle Foundation. (2008). *Americans overwhelmingly believe electronic personal health records could improve their health*. Retrieved April 22, 2011, from

<http://www.markle.org/sites/default/files/ResearchBrief-200806.pdf>

Professor Alan F. Westin developed and Knowledge Networks conducted a survey among 1,580 American adults (18+) nationwide, May 13-22, 2008, commissioned by the Markle Foundation. The survey examined public opinions on the potential and privacy considerations of individually controlled electronic personal health records (PHRs).

It is the first national survey to explore consumer perceptions about PHRs in the context of the entrance of Google, Intuit, Microsoft, Revolution Health and WebMD in the marketplace, and to measure perceptions of the importance of privacy practices in consumers' decision to adopt such services. The results documented firm attitudes in a

majority of adults surveyed regarding privacy practices in the unfolding world of online PHR services.

McInnes, D. K., Solomon, J. L., Bokhour, B. G., Asch, S. M., Ross, D., Nazi, K. M., & Gifford, A. L. (2011). Use of electronic personal health record systems to encourage HIV screening: An exploratory study of patient and provider perspectives. *BMC Research Notes*, 4, 295. doi:10.1186/1756-0500-4-295

ABSTRACT: BACKGROUND: When detected, HIV can be effectively treated with antiretroviral therapy. Nevertheless in the U.S. approximately 25% of those who are HIV-infected do not know it. Much remains unknown about how to increase HIV testing rates. New Internet outreach methods have the potential to increase disease awareness and screening among patients, especially as electronic personal health records (PHRs) become more widely available. In the US Department of Veterans' Affairs medical care system, 900,000 veterans have indicated an interest in receiving electronic health-related communications through the PHR. Therefore we sought to evaluate the optimal circumstances and conditions for outreach about HIV screening. In an exploratory, qualitative research study we examined patient and provider perceptions of Internet-based outreach to increase HIV screening among veterans who use the Veterans Health Administration (VHA) health care system. **FINDINGS:** We conducted two rounds of focus groups with veterans and healthcare providers at VHA medical centers. The study's first phase elicited general perceptions of an electronic outreach program to increase screening for HIV, diabetes, and high cholesterol. Using phase 1 results, outreach message texts were drafted and then presented to participants in the second phase. Analysis followed modified grounded theory. 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. Patients saw little difference between messages about HIV versus about diabetes and cholesterol. Providers, however, felt patients would disapprove of HIV-related messages due to stigma. Providers expected increased workload from the electronic outreach, and thus suggested adding primary care resources and devising methods to smooth the flow of patients getting screened. When provided a choice between unsecured emails versus PHRs as the delivery mechanism for disease screening messages, both patients and providers preferred PHRs.

CONCLUSIONS: 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.

Montelius, E., Astrand, B., Hovstadius, B., & Petersson, G. (2008). Individuals appreciate having their medication record on the web: A survey of attitudes to a national pharmacy register. *Journal of Medical Internet Research, 10(4)*, e35.

doi:10.2196/jmir.1022

BACKGROUND: Many patients receive health care in different settings. Thus, a limitation of clinical care may be inaccurate medication lists, since data exchange between settings is often lacking and patients do not regularly self-report on changes in their medication. Health care professionals and patients are both interested in

utilizing electronic health information. However, opinion is divided as to who should take responsibility for maintaining personal health records. In Sweden, the government has passed a law to enforce and fund a national register of dispensed medications. The register comprises all individuals with dispensed medications (6.4 million individuals, September 2006) and can be accessed by the individual online via "My dispensed medications". The individual has the right to restrict the accessibility of the information in health care settings. OBJECTIVE: The aim of the present study was to evaluate the users' attitudes towards their access to "My dispensed medications" as part of a new interactive Internet service on prescribed medications. METHOD: A password-protected Web survey was conducted among a first group of users of "My dispensed medications". Data was anonymously collected and analyzed with regard to the usefulness and design of the Web site, the respondents' willingness to discuss their "My dispensed medications" with others, their reasons for access, and their source of information about the service. RESULTS: During the study period (January-March, 2007), all 7860 unique site visitors were invited to answer the survey. Invitations were accepted by 2663 individuals, and 1716 responded to the online survey yielding a view rate of 21.8% (1716/7860) and a completion rate of 64.4% (1716/2663). The completeness rate for each question was in the range of 94.9% (1629/1716) to 99.5% (1707/1716). In general, the respondents' expectations of the usefulness of "My dispensed medications" were high (total median grade 5; Inter Quartile Range [IQR] 3, on a scale 1-6). They were also positive about the design of the Web site (total median grade 5; IQR 1, on a scale 1-6). The high grades were not dependent on age or number of drugs. A majority of the respondents, 60.4% (1037/1716), had learned about "My

dispensed medications" from pharmacies. 70.4% (1208/1716) of all respondents said they visited "My dispensed medications" to get control or an overview of their drugs. Getting control was a more common ($P < .001$) answer for the elderly (age 75 or above), whereas curiosity was more common ($P < .001$) for the younger age group (18-44 years). CONCLUSION: We found that users of the provider-based personal medication record "My dispensed medications" appreciated the access to their record. Since we found that the respondents liked the design of the Web site and perceived that the information was easy to understand, the study provided no reason for system changes. However, a need for more information about the register, and to extend its use, was recognized.

Or, C. K., Karsh, B. T., Severtson, D. J., Burke, L. J., Brown, R. L., & Brennan, P. F. (2011).

Factors affecting home care patients' acceptance of a web-based interactive self-management technology. *Journal of the American Medical Informatics Association*, 18(1), 51-59. doi:10.1136/jamia.2010.007336

OBJECTIVE: With the advent of personal health records and other patient-focused health technologies, there is a growing need to better understand factors that contribute to acceptance and use of such innovations. In this study, we employed the Unified Theory of Acceptance and Use of Technology as the basis for determining what predicts patients' acceptance (measured by behavioral intention) and perceived effective use of a web-based, interactive self-management innovation among home care patients. DESIGN: Cross-sectional secondary analysis of data from a randomized field study evaluating a technology-assisted home care nursing practice with adults with chronic cardiac disease. MEASUREMENT AND ANALYSIS: A questionnaire was

designed based on validated measurement scales from prior research and was completed by 101 participants for measuring the acceptance constructs as part of the parent study protocol. Latent variable modeling with item parceling guided assessment of patients' acceptance. RESULTS: Perceived usefulness accounted for 53.9% of the variability in behavioral intention, the measure of acceptance. Together, perceived usefulness, health care knowledge, and behavioral intention accounted for 68.5% of the variance in perceived effective use. Perceived ease of use and subjective norm indirectly influenced behavioral intention, through perceived usefulness. Perceived ease of use and subjective norm explained 48% of the total variance in perceived usefulness. CONCLUSION: The study demonstrates that perceived usefulness, perceived ease of use, subjective norm, and healthcare knowledge together predict most of the variance in patients' acceptance and self-reported use of the web-based self-management technology.

Patel, V. N., Abramson, E., Edwards, A. M., Cheung, M. A., Dhopeswarkar, R. V., & Kaushal, R. (2011). Consumer attitudes toward personal health records in a beacon community. *The American Journal of Managed Care*, 17(4), e104-20.

OBJECTIVE: To characterize consumers' attitudes about personal health records (PHRs), electronic tools that enable consumers to securely access, manage, and share their health information, in a community participating in health information technology initiatives. STUDY DESIGN: Cross-sectional study. METHODS: A random-digit-dial telephone survey about PHRs was conducted among adult residents of New York State's greater Buffalo region. Multivariate regression analyses identified factors associated with potential PHR use. RESULTS: We obtained a 79% (n = 200) response

rate. Many respondents (70%) would potentially use PHRs. Consumers wanted PHRs to incorporate an array of information, including immunization records (89%) and providers visited (88%). They expressed interest in several online activities, including accessing their family members' healthcare information (71%). Potential PHR use was associated with perceptions that PHRs would improve privacy and security of medical information (odds ratio [OR] 4.7; 95% confidence interval [CI] 1.1, 20.1), understanding regarding health (OR 3.7; 95% CI 1.3, 11.1), and overall quality of care (OR 3.6; 95% CI 1.2, 10.6). Potential PHR use was associated with annual household income of more than \$30,000 (OR 3.9; 95% CI 1.3, 11.9) and experience looking up health information online (OR 3.0; 95% CI 1.1, 8.1). CONCLUSIONS: Consumers expressed great interest in using PHRs and wanted comprehensive PHRs. However, the "digital divide" between those with varying levels of Internet experience and concerns about PHRs' effect on privacy and security of medical information may limit use. Designing PHRs that incorporate consumer preferences and developing policies that address these barriers may increase consumers' PHR use.

Patel, V. N., Dhopeswarkar, R. V., Edwards, A., Barron, Y., Sparenborg, J., & Kaushal, R. (2010). Consumer Support for Health Information Exchange and Personal Health Records: A Regional Health Information Organization Survey. *Journal of Medical Systems*, doi:10.1007/s10916-010-9566-0

In order to characterize consumer support for electronic health information exchange (HIE) and personal health records (PHRs) in a community where HIE is underway, we conducted a survey of English speaking adults who visited primary care practices participating in a regional community-wide clinical data exchange, during August,

2008. Amongst the 117 respondents, a majority supported physicians' use of HIE (83%) or expressed interest in potentially using PHRs (76%). Consumers' comfort sending personal information electronically over the Internet and their perceptions regarding the potential benefits of HIE were independently associated with their support for HIE. Consumers' prior experience using the Internet to manage their healthcare, perceptions regarding the potential benefits of PHRs and college education were independently associated with potential PHR use. Bolstering consumer support for HIE and PHRs will require addressing privacy and security concerns, demonstrating clinical benefits, and reaching out to those who are less educated and computer literate.

Teixeira, P. A., Gordon, P., Camhi, E., & Bakken, S. (2011). HIV patients' willingness to share personal health information electronically. [Willingness to share PHI was positively associated with trust and respect of clinicians.] *Patient Education and Counseling*, 84(2), e9-12. doi:10.1016/j.pec.2010.07.013

OBJECTIVE: To assess the attitudes of persons living with HIV/AIDS (PLWH) towards having their personal health information (PHI) stored and shared electronically.

METHODS: PLWH (n = 93) in New York City completed surveys using audio computer-assisted self-interview (ACASI) that assessed willingness to share their PHI with various people and entities via a secure electronic network. The survey also included questions on satisfaction with and trust of health care providers, current health, HIV-associated stigma, and frequency of internet access. Data were analyzed with descriptive and multivariate statistical methods. RESULTS: The majority (84%) of individuals were willing to share their PHI with clinicians involved in their care. Fewer

individuals (39%) were as willing to share with non-clinical staff. Willingness to share PHI was positively associated with trust and respect of clinicians. CONCLUSION: PLWH accepted clinicians' need for access to accurate information. Patients' trust in their primary care providers highlights the importance of the clinician-patient relationship which can be used to engage patients support for health information exchange initiatives. PRACTICE IMPLICATIONS: As electronic storage and sharing of PHI is increasing, clinicians and PLWH should discuss patients' attitudes towards sharing PHI electronically.

van Empel, I. W., Hermens, R. P., Akkermans, R. P., Hollander, K. W., Nelen, W. L., & Kremer, J. A. (2011). Organizational determinants of patient-centered fertility care: A multilevel analysis. *Fertility and Sterility*, 95(2), 513-519. doi:10.1016/j.fertnstert.2010.08.021

OBJECTIVE: To identify organizational determinants of positive patient experiences with fertility care, with the goal of improving patient centeredness of care. DESIGN: Cross-sectional survey. SETTING: One large university clinic and 12 medium-sized fertility clinics in the Netherlands. PATIENT(S): Three hundred and sixty-nine couples receiving medically assisted reproduction in one of the participating clinics between March and May 2008. INTERVENTION(S): None. MAIN OUTCOME MEASURE(S): Organizational determinants of patients' experiences with patient centeredness in fertility care. RESULT(S): Of the patients during the relevant period, 78% of the women and 76% of their partners participated in the study. Infertile couples who have a lead physician, have access to an electronic personal health record, or see trained fertility nurses have more positive experiences with aspects of patient-centered care, like continuity of care and partner involvement. Moreover, receiving a treatment other

than in vitro fertilization was negatively associated with the perceived patient centeredness of care. The identified determinants explained 5.1% to 22.4% of the total variance. CONCLUSION(S): This study provides organizational determinants of patients' experiences with fertility care on numerous facets of patient centeredness. These organizational determinants can be used as valuable tools to enable clinics to provide a more positive patient experience.

Wagner, P. J., Howard, S. M., Bentley, D. R., Seol, Y. H., & Sodomka, P. (2010). Incorporating patient perspectives into the personal health record: implications for care and caring. *Perspectives in Health Information Management*, 7, 1e.

Electronic personal health records (ePHRs) can potentially maximize access and coordination of health information and improve patient/clinician collaboration, patient self-management, and health outcomes. Most ePHRs are designed by vendors, physicians, and other proprietary partners and have neglected the patient perspective. This study sought to incorporate patient feedback into an existing ePHR system. Patients participated in a semistructured interview after one to two weeks of using an ePHR. Interviews addressed strengths and weaknesses of the PHR. Two iterations of interviews, referred to as Wave 1 and Wave 2, occurred sequentially. An iterative process of theme identification was used, and three theme categories (User, System Acceptance, and Technology) were identified in the two waves. Seven technology themes with 40 specific questions were identified and were rank ordered by importance and feasibility, and 20 suggestions were subsequently implemented into the ePHR. Thus, incorporating patient feedback on specific utilities and functionality into an existing ePHR is possible.

Weitzman, E. R., Kaci, L., & Mandl, K. D. (2009). Acceptability of a personally controlled health record in a community-based setting: Implications for policy and design. *Journal of Medical Internet Research*, 11(2), e14. doi:10.2196/jmir.1187

BACKGROUND: Consumer-centered health information systems that address problems related to fragmented health records and disengaged and disempowered patients are needed, as are information systems that support public health monitoring and research. Personally controlled health records (PCHRs) represent one response to these needs. PCHRs are a special class of personal health records (PHRs) distinguished by the extent to which users control record access and contents. Recently launched PCHR platforms include Google Health, Microsoft's HealthVault, and the Dossia platform, based on Indivo. OBJECTIVE: To understand the acceptability, early impacts, policy, and design requirements of PCHRs in a community-based setting. METHODS: Observational and narrative data relating to acceptability, adoption, and use of a personally controlled health record were collected and analyzed within a formative evaluation of a PCHR demonstration. Subjects were affiliates of a managed care organization run by an urban university in the northeastern United States. Data were collected using focus groups, semi-structured individual interviews, and content review of email communications. Subjects included: n = 20 administrators, clinicians, and institutional stakeholders who participated in pre-deployment group or individual interviews; n = 52 community members who participated in usability testing and/or pre-deployment piloting; and n = 250 subjects who participated in the full demonstration of which n = 81 initiated email communications to troubleshoot problems or provide feedback. All data were formatted as narrative text and coded

thematically by two independent analysts using a shared rubric of a priori defined major codes. Sub-themes were identified by analysts using an iterative inductive process. Themes were reviewed within and across research activities (ie, focus group, usability testing, email content review) and triangulated to identify patterns. RESULTS: Low levels of familiarity with PCHRs were found as were high expectations for capabilities of nascent systems. Perceived value for PCHRs was highest around abilities to co-locate, view, update, and share health information with providers. Expectations were lowest for opportunities to participate in research. Early adopters perceived that PCHR benefits outweighed perceived risks, including those related to inadvertent or intentional information disclosure. Barriers and facilitators at institutional, interpersonal, and individual levels were identified. Endorsement of a dynamic platform model PCHR was evidenced by preferences for embedded searching, linking, and messaging capabilities in PCHRs; by high expectations for within-system tailored communications; and by expectation of linkages between self-report and clinical data. CONCLUSIONS: Low levels of awareness/preparedness and high expectations for PCHRs exist as a potentially problematic pairing. Educational and technical assistance for lay users and providers are critical to meet challenges related to: access to PCHRs, especially among older cohorts; workflow demands and resistance to change among providers; inadequate health and technology literacy; clarification of boundaries and responsibility for ensuring accuracy and integrity of health information across distributed data systems; and understanding confidentiality and privacy risks. Continued demonstration and evaluation of PCHRs is essential to advancing their use.

Weitzman, E. R., Kaci, L., & Mandl, K. D. (2010). Sharing medical data for health research:

The early personal health record experience. *Journal of Medical Internet Research*, 12(2), e14. doi:10.2196/jmir.1356

BACKGROUND: Engaging consumers in sharing information from personally controlled health records (PCHRs) for health research may promote goals of improving care and advancing public health consistent with the federal Health Information Technology for Economic and Clinical Health (HITECH) Act. Understanding consumer willingness to share data is critical to advancing this model. **OBJECTIVE:** The objective was to characterize consumer willingness to share PCHR data for health research and the conditions and contexts bearing on willingness to share. **METHODS:** A mixed method approach integrating survey and narrative data was used. Survey data were collected about attitudes toward sharing PCHR information for health research from early adopters (n = 151) of a live PCHR populated with medical records and self-reported behavioral and social data. Data were analyzed using descriptive statistics and logistic regression to characterize willingness, conditions for sharing, and variations by sociodemographic factors. Narrative data were collected through semistructured focus group and one-on-one interviews with a separate sample of community members (n = 30) following exposure to PCHR demonstrations. Two independent analysts coded narrative data for major and minor themes using a shared rubric of a priori defined codes and an iterative inductive process. Findings were triangulated with survey results to identify patterns. **RESULTS:** Of PHCR users, 138 out of 151 (91%) were willing to share medical information for health research with 89 (59%) favoring an opt-in sharing model. Willingness to share was conditioned by anonymity, research

use, engagement with a trusted intermediary, transparency around PCHR access and use, and payment. Consumer-determined restrictions on content and timing of sharing may be prerequisites to sharing. 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 (unadjusted odds ratio [OR] = 2.89, 95% confidence interval [CI] 1.10 - 7.62, P = .03). Participants over age 50 were less likely than younger participants to report that payment would increase willingness to share (unadjusted OR = 0.94, 95% CI 0.91 - 0.96, P < .001). Students were more likely than nonstudents to report that payment would increase their willingness to share (unadjusted OR 9.62, 95% CI 3.44 - 26.87, P < .001). Experiencing a public health emergency may increase willingness to share especially among persons over 50 (unadjusted OR 1.03, 95% CI 1.01 - 1.05, P = .02); however, students were less likely than non-students to report this attitude (unadjusted OR 0.13, 95% CI 0.05 - 0.36, P < .001). 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 (unadjusted OR 0.61, 95% CI 0.38 - 0.97, P = .04). CONCLUSIONS: 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.

Barriers – Annotated Bibliography

Anoshiravani, A., Gaskin, G., Kopetsky, E., Sandborg, C., & Longhurst, C. A. (2011).

Implementing an Interoperable Personal Health Record in Pediatrics: Lessons Learned at an Academic Children's Hospital. *Journal of Participatory Medicine*, 3, e30.

This paper describes the development of an innovative health information technology creating a bidirectional link between the electronic medical record (EMR) of an academic children's hospital and a commercially available, interoperable personal health record (PHR). The goal of the PHR project has been to empower pediatric patients and their families to play a more active role in understanding, accessing, maintaining, and sharing their personal health information to ultimately improve health outcomes. The most notable challenges proved more operational and cultural than technological. Our experience demonstrates that an interoperable PHR is technically and culturally achievable at a pediatric academic medical center.

Recognizing the complex social, cultural, and organizational contexts of these systems is important for overcoming barriers to a successful implementation.

Benhamou, P. Y. (2011). Improving diabetes management with electronic health records and patients' health records. *Diabetes & Metabolism*, 37(Suppl 4), S53-6.

doi:10.1016/S1262-3636(11)70966-1

The lack of patient engagement and clinical inertia both contribute to suboptimal diabetes care. However, both obstacles are amenable to informatics- and Internet-

based interventions. The use of electronic medical records (EMRs) is now established as being useful for improving diabetes care. Intelligent records that integrate computerized decision-support systems are now able to recommend care protocols tailored to risk levels. Web-based personal health record (PHR) systems, shared with healthcare providers, could also provide added value by promoting self-management of the behaviours related to diabetes. These Web-based programmes include patients' access to EMRs, uploading of glucose monitoring results, a glucose diary, secure e-mail with providers, manual or automated feedback on blood glucose readings and other risk factors, an educational website, and an online diary for entering personal information on exercise, diet and medication. The integration of Web-based patients' systems into the EMR used by physicians is the next frontier. In addition, the input from "smartphones" that are able to provide real-time support to patients could contribute to the reorganization of diabetes care. Convincing data on HbA(1c) improvements with such systems are available for type 2 diabetes, but are still equivocal for type 1 diabetes. Obstacles include patients' compliance with the technology, their ergonomic design and the need to reimburse providers for their care. Designing appropriate electronic tools and tailoring them to the conditions in France merits our attention.

Bonacina, S., & Pinciroli, F. (2010). An ontology-based tool for the correspondences between specialist and consumer medical lexicons for the geriatrics domain. *Studies in Health Technology and Informatics*, 156, 128-137.

New services devoted to improve personalized healthcare are emerging from information technology developments. Personal health record systems allow the

patients to participate actively in their healthcare process. However, the dissemination and use of personal health record systems face with some barriers, for example low health literacy that leads to discrepancy in understanding medical concepts. While it is important to present health information using consumer-familiar terms in consumer applications, consistently converting medical terms to consumer-familiar ones is a challenging task. We designed and developed both an ontology-like taxonomic structure devoted to the Geriatrics domain for the outpatient and a software tool, for carrying out the matching between the medical vocabulary of the consumer and that of the doctor from the outpatient's and their family point of view.

Detmer, D., Bloomrosen, M., Raymond, B., & Tang, P. (2008). Integrated personal health records: Transformative tools for consumer-centric care. *BMC Medical Informatics and Decision Making*, 8, 45. doi:10.1186/1472-6947-8-45

BACKGROUND: Integrated personal health records (PHRs) offer significant potential to stimulate transformational changes in health care delivery and self-care by patients. In 2006, an invitational roundtable sponsored by Kaiser Permanente Institute, the American Medical Informatics Association, and the Agency for Healthcare Research and Quality was held to identify the transformative potential of PHRs, as well as barriers to realizing this potential and a framework for action to move them closer to the health care mainstream. This paper highlights and builds on the insights shared during the roundtable. DISCUSSION: While there is a spectrum of dominant PHR models, (standalone, tethered, integrated), the authors state that only the integrated model has true transformative potential to strengthen consumers' ability to manage their own health care. Integrated PHRs improve the quality, completeness, depth, and

accessibility of health information provided by patients; enable facile communication between patients and providers; provide access to health knowledge for patients; ensure portability of medical records and other personal health information; and incorporate auto-population of content. Numerous factors impede widespread adoption of integrated PHRs: obstacles in the health care system/culture; issues of consumer confidence and trust; lack of technical standards for interoperability; lack of HIT infrastructure; the digital divide; uncertain value realization/ROI; and uncertain market demand. Recent efforts have led to progress on standards for integrated PHRs, and government agencies and private companies are offering different models to consumers, but substantial obstacles remain to be addressed. Immediate steps to advance integrated PHRs should include sharing existing knowledge and expanding knowledge about them, building on existing efforts, and continuing dialogue among public and private sector stakeholders. SUMMARY: Integrated PHRs promote active, ongoing patient collaboration in care delivery and decision making. With some exceptions, however, the integrated PHR model is still a theoretical framework for consumer-centric health care. The authors pose questions that need to be answered so that the field can move forward to realize the potential of integrated PHRs. How can integrated PHRs be moved from concept to practical application? Would a coordinating body expedite this progress? How can existing initiatives and policy levers serve as catalysts to advance integrated PHRs?

Fricton, J. R., & Davies, D. (2008). Personal health records to improve health information exchange and patient safety. In K. Henriksen, J. B. Battles, M. A. Keyes & M. L. Grady (Eds.), *Advances in Patient Safety: New Directions and Alternative Approaches (Vol. 4:*

Technology and Medication Safety). Rockville (MD): Agency for Healthcare Research and Quality. Retrieved

from http://www.ahrq.gov/downloads/pub/advances2/vol4/advances-fricton_21.pdf

The personal health record (PHR) is proposed as an innovative solution to the problems of fragmented communication and lack of interoperability among diverse electronic medical record (EMR) systems. It provides a single source (the patient's PHR) for authentication and remote access of the health information data from all EMR systems. A voluntary survey was offered to selected patients, caregivers, and health providers of the Willmar, MN, PHR project to determine if a PHR was useful to these stakeholders, and if so, what aspects of a PHR would be most helpful in caring for patients. The survey responses revealed nearly universal interest by both patients and health providers in using the PHR regularly for accessing and exchanging health information, including medication and medical history reconciliation and patient education. The highest utilization would result from a community-based PHR implementation that was owned and controlled by the consumer and was portable among providers, plans, and employers.

Gaskin, G. L., Longhurst, C. A., Slayton, R., & Das, A. K. (2011). Sociotechnical challenges of developing an interoperable personal health record: Lessons learned. *Applied Clinical Informatics*, 2(4), 406-419. doi:10.4338/ACI-2011-06-RA-0035

OBJECTIVES: To analyze sociotechnical issues involved in the process of developing an interoperable commercial Personal Health Record (PHR) in a hospital setting, and to create guidelines for future PHR implementations. METHODS: This qualitative study utilized observational research and semi-structured interviews with 8 members of the

hospital team, as gathered over a 28 week period of developing and adapting a vendor-based PHR at Lucile Packard Children's Hospital at Stanford University. A grounded theory approach was utilized to code and analyze over 100 pages of typewritten field notes and interview transcripts. This grounded analysis allowed themes to surface during the data collection process which were subsequently explored in greater detail in the observations and interviews. RESULTS: Four major themes emerged: (1) Multidisciplinary teamwork helped team members identify crucial features of the PHR; (2) Divergent goals for the PHR existed even within the hospital team; (3) Differing organizational conceptions of the end-user between the hospital and software company differentially shaped expectations for the final product; (4) Difficulties with coordination and accountability between the hospital and software company caused major delays and expenses and strained the relationship between hospital and software vendor. CONCLUSIONS: Though commercial interoperable PHRs have great potential to improve healthcare, the process of designing and developing such systems is an inherently sociotechnical process with many complex issues and barriers. This paper offers recommendations based on the lessons learned to guide future development of such PHRs.

Haggstrom, D. A., Saleem, J. J., Russ, A. L., Jones, J., Russell, S. A., & Chumbler, N. R. (2011). Lessons learned from usability testing of the VA's personal health record. *Journal of the American Medical Informatics Association*, 18 Suppl 1(Suppl 1), i13-7.
doi:10.1136/amiajnl-2010-000082

In order to create user-centered design information to guide the development of personal health records (PHRs), 24 patients participated in usability assessments of

VA's MyHealtheVet program. 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. Twenty-five percent of users successfully completed registration. Individuals preferred prescription numbers over names, sometimes due to privacy concerns. Only efficiency in prescription refills was significantly better than target values. Users wanted to print their information to share with their doctors, and questioned the value of MyHealtheVet search functions over existing online health information. In summary, PHR registration must balance simplicity and security, usability tests guide how PHRs can tailor functions to individual preferences, PHRs add value to users' data by making information more accessible and understandable, and healthcare organizations should build trust for PHR health content.

Kahn, J. S., Aulakh, V., & Bosworth, A. (2009). What it takes: Characteristics of the ideal personal health record. *Health Affairs (Project Hope)*, 28(2), 369-376.

doi:10.1377/hlthaff.28.2.369

There is a gap between today's personal health records (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.

Keselman, A., Slaughter, L., Smith, C. A., Kim, H., Divita, G., Browne, A., . . . Zeng-Treitler, Q. (2007). Towards consumer-friendly PHRs: patients' experience with reviewing their

health records. *AMIA ...Annual Symposium Proceedings, 2007*, 399-403.

Consumer-friendly Personal Health Records (PHRs) have the potential of providing patients with the basis for taking an active role in their healthcare. However, few studies focused on the features that make health records comprehensible for lay audiences. This paper presents a survey of patients' experience with reviewing their health records, in order to identify barriers to optimal record use. The data are analyzed via descriptive statistical and thematic analysis. The results point to providers' notes, laboratory test results and radiology reports as the most difficult records sections for lay reviewers. Professional medical terminology, lack of explanations of complex concepts (e.g., lab test ranges) and suboptimal data ordering emerge as the most common comprehension barriers. While most patients today access their records in paper format, electronic PHRs present much more opportunities for providing comprehension support.

Kim, E. H., Stolyar, A., Lober, W. B., Herbaugh, A. L., Shinstrom, S. E., Zierler, B. K., . . . Kim, Y.

(2009). Challenges to using an electronic personal health record by a low-income elderly population. *Journal of Medical Internet Research*, 11(4), e44. Retrieved from <http://www.jmir.org/2009/4/e44/>

BACKGROUND: Electronic personal health records (PHRs) are increasingly recognized and used as a tool to address various challenges stemming from the scattered and incompatible personal health information that exists in the contemporary US health care system. Although activity around PHR development and deployment has

increased in recent years, little has been reported regarding the use and utility of PHRs among low-income and/or elderly populations. OBJECTIVE: The aim was to assess the use and utility of PHRs in a low-income, elderly population. METHODS: We deployed a Web-based, institution-neutral PHR system, the Personal Health Information Management System (PHIMS), in a federally funded housing facility for low-income and elderly residents. We assessed use and user satisfaction through system logs, questionnaire surveys, and user group meetings. RESULTS: Over the 33-month study period, 70 residents participated; this number was reduced to 44 by the end of the study. Although the PHIMS was available for free and personal assistance and computers with Internet connection were provided without any cost to residents, only 13% (44/330) of the eligible residents used the system, and system usage was limited. Almost one half of the users (47%, 33/70) used the PHIMS only on a single day. Use was also highly correlated with the availability of in-person assistance; 77% of user activities occurred while the assistance was available. Residents' ability to use the PHR system was limited by poor computer and Internet skills, technophobia, low health literacy, and limited physical/cognitive abilities. Among the 44 PHIMS users, 14 (32%) responded to the questionnaire. In this selected subgroup of survey participants, the majority (82%, 9/11) used the PHIMS three times or more and reported that it improved the quality of overall health care they received. CONCLUSIONS: Our findings suggest that those who can benefit the most from a PHR system may be the least able to use it. Disparities in access to and use of computers, the Internet, and PHRs may exacerbate health care inequality in the future.

Lober, W. B., Zierler, B., Herbaugh, A., Shinstrom, S. E., Stolyar, A., Kim, E. H., & Kim, Y.

(2006). Barriers to the use of a personal health record by an elderly population. *AMIA Annual Symposium Proceedings, 2006*, 514-518.

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

Miller, H., Vandenbosch, B., Ivanov, D., & Black, P. (2007). Determinants of personal health record use: a large population study at Cleveland Clinic. *Journal of Healthcare Information Management, 21*(3), 44-48.

While research in other domains leads us to expect that some patients will be more predisposed to technology adoption than others, the factors that indicate propensity for use are not clear. In this study, researchers extracted the demographic and usage information of 63,295 people who had registered to use eCleveland Clinic MyChart. Of those, 12,101 had never logged onto the system and were termed registered never users. Registered users are more likely to be Caucasian and married than registered never users. The only predictors of degree of PHR use among the registered users are number of diagnoses from the EMR problem list and the number of clinical encounters. Hence, Cleveland Clinic's PHR portal appears to be most useful to patients who are sicker and greater consumers of healthcare.

Tang, P. C., Ash, J. S., Bates, D. W., Overhage, J. M., & Sands, D. Z. (2006). Personal health records: Definitions, benefits, and strategies for overcoming barriers to adoption. *Journal of the American Medical Informatics Association*, 13(2), 121-126. doi:10.1197/jamia.M2025

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

Turvey, C. L., Zulman, D. M., Nazi, K. M., Wakefield, B. J., Woods, S. S., Hogan, T. P., . . .

McInnes, K. (2012). Transfer of Information from Personal Health Records: A Survey of Veterans Using My HealtheVet. *Telemedicine Journal and e-Health*, doi:10.1089/tmj.2011.0109

Abstract Objective: Personal health records provide patients with ownership of their health information and allow them to share information with multiple healthcare providers. However, the usefulness of these records relies on patients understanding and using their records appropriately. My HealtheVet is a Web-based patient portal containing a personal health record administered by the Veterans Health Administration. The goal of this study was to explore veterans' interest and use of My HealtheVet to transfer and share information as well as to identify opportunities to increase veteran use of the My HealtheVet functions. Materials and Methods: Two waves of data were collected in 2010 through an American Customer Satisfaction Index Web-based survey. A random sample of veterans using My HealtheVet was invited to participate in the survey conducted on the My HealtheVet portal through a Web-based pop-up browser window. Results: Wave One results (n=25,898) found that 41% of veterans reported printing information, 21% reported saving information electronically, and only 4% ever sent information from My HealtheVet to another person. In Wave Two (n=18,471), 30% reported self-entering medication information, with 18% sharing this information with their Veterans Affairs (VA) provider and 9.6% sharing with their non-VA provider. Conclusion: Although veterans are transferring important medical information from their personal health records, increased education and awareness are needed to increase use. Personal health records 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.

Van Deursen, T., Koster, P., & Petkovic, M. (2008). Reliable personal health records. *Studies in Health Technology and Informatics*, 136, 484-489.

A number of applications based on personal health records (PHRs) are emerging in the field of health care and wellness. PHRs empower patients by giving them control over their health data. Health data for PHRs can be supplied by patients, wellness providers and health care providers. Health care providers may use the PHRs to provide medical care. Unfortunately, the quality of the health data in PHRs cannot be guaranteed in all cases. For example, consider cases where non-professionals such as patients and wellness providers supply data. To address this problem, we present in this paper a system that provides health care professionals with an indication of the quality of health data in a PHR. This indication is based on the reputation of the supplier and on metadata provided by measurement devices. The proposed reputation system mimics the way in which trust in health data and their suppliers is built in the real world. The system introduces minimal overhead for health care providers and patients.

Weitzman, E. R., Kaci, L., & Mandl, K. D. (2009). Acceptability of a personally controlled health record in a community-based setting: Implications for policy and design. *Journal of Medical Internet Research*, 11(2), e14. doi:10.2196/jmir.1187

BACKGROUND: Consumer-centered health information systems that address problems related to fragmented health records and disengaged and disempowered patients are needed, as are information systems that support public health monitoring and research. Personally controlled health records (PCHRs) represent one response to these needs. PCHRs are a special class of personal health records (PHRs) distinguished by the extent to which users control record access and contents. Recently launched

PCHR platforms include Google Health, Microsoft's HealthVault, and the Dossia platform, based on Indivo. OBJECTIVE: To understand the acceptability, early impacts, policy, and design requirements of PCHRs in a community-based setting. METHODS: Observational and narrative data relating to acceptability, adoption, and use of a personally controlled health record were collected and analyzed within a formative evaluation of a PCHR demonstration. Subjects were affiliates of a managed care organization run by an urban university in the northeastern United States. Data were collected using focus groups, semi-structured individual interviews, and content review of email communications. Subjects included: n = 20 administrators, clinicians, and institutional stakeholders who participated in pre-deployment group or individual interviews; n = 52 community members who participated in usability testing and/or pre-deployment piloting; and n = 250 subjects who participated in the full demonstration of which n = 81 initiated email communications to troubleshoot problems or provide feedback. All data were formatted as narrative text and coded thematically by two independent analysts using a shared rubric of a priori defined major codes. Sub-themes were identified by analysts using an iterative inductive process. Themes were reviewed within and across research activities (ie, focus group, usability testing, email content review) and triangulated to identify patterns. RESULTS: Low levels of familiarity with PCHRs were found as were high expectations for capabilities of nascent systems. Perceived value for PCHRs was highest around abilities to co-locate, view, update, and share health information with providers. Expectations were lowest for opportunities to participate in research. Early adopters perceived that PCHR benefits outweighed perceived risks, including those related to inadvertent or

intentional information disclosure. Barriers and facilitators at institutional, interpersonal, and individual levels were identified. Endorsement of a dynamic platform model PCHR was evidenced by preferences for embedded searching, linking, and messaging capabilities in PCHRs; by high expectations for within-system tailored communications; and by expectation of linkages between self-report and clinical data.

CONCLUSIONS: Low levels of awareness/preparedness and high expectations for PCHRs exist as a potentially problematic pairing. Educational and technical assistance for lay users and providers are critical to meet challenges related to: access to PCHRs, especially among older cohorts; workflow demands and resistance to change among providers; inadequate health and technology literacy; clarification of boundaries and responsibility for ensuring accuracy and integrity of health information across distributed data systems; and understanding confidentiality and privacy risks.

Continued demonstration and evaluation of PCHRs is essential to advancing their use.

Weitzman, E. R., Kaci, L., & Mandl, K. D. (2010). Sharing medical data for health research:

The early personal health record experience. *Journal of Medical Internet Research*, 12(2), e14. doi:10.2196/jmir.1356

BACKGROUND: Engaging consumers in sharing information from personally controlled health records (PCHRs) for health research may promote goals of improving care and advancing public health consistent with the federal Health Information Technology for Economic and Clinical Health (HITECH) Act. Understanding consumer willingness to share data is critical to advancing this model. **OBJECTIVE:** The objective was to characterize consumer willingness to share PCHR data for health research and the conditions and contexts bearing on willingness to share. **METHODS:** A mixed method

approach integrating survey and narrative data was used. Survey data were collected about attitudes toward sharing PCHR information for health research from early adopters (n = 151) of a live PCHR populated with medical records and self-reported behavioral and social data. Data were analyzed using descriptive statistics and logistic regression to characterize willingness, conditions for sharing, and variations by sociodemographic factors. Narrative data were collected through semistructured focus group and one-on-one interviews with a separate sample of community members (n = 30) following exposure to PCHR demonstrations. Two independent analysts coded narrative data for major and minor themes using a shared rubric of a priori defined codes and an iterative inductive process. Findings were triangulated with survey results to identify patterns. RESULTS: Of PHCR users, 138 out of 151 (91%) were willing to share medical information for health research with 89 (59%) favoring an opt-in sharing model. Willingness to share was conditioned by anonymity, research use, engagement with a trusted intermediary, transparency around PCHR access and use, and payment. Consumer-determined restrictions on content and timing of sharing may be prerequisites to sharing. 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 (unadjusted odds ratio [OR] = 2.89, 95% confidence interval [CI] 1.10 - 7.62, P = .03). Participants over age 50 were less likely than younger participants to report that payment would increase willingness to share (unadjusted OR = 0.94, 95% CI 0.91 - 0.96, P < .001). Students were more likely than nonstudents to report that payment

would increase their willingness to share (unadjusted OR 9.62, 95% CI 3.44 - 26.87, $P < .001$). Experiencing a public health emergency may increase willingness to share especially among persons over 50 (unadjusted OR 1.03, 95% CI 1.01 - 1.05, $P = .02$); however, students were less likely than non-students to report this attitude (unadjusted OR 0.13, 95% CI 0.05 - 0.36, $P < .001$). 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 (unadjusted OR 0.61, 95% CI 0.38 - 0.97, $P = .04$). CONCLUSIONS: 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.

Wiljer, D., Urowitz, S., Apatu, E., Leonard, K., Quartey, N. K., & Catton, P. (2010).

Understanding the support needs of patients accessing test results online. PHRs offer great promise, but support issues must be addressed to ensure appropriate access. *Journal of Healthcare Information Management*, 24(1), 57-63.

Personal health records (PHR) offer great promise in transforming the patient experience, but a number of support issues must be addressed to ensure that patients have appropriate access to their health information. Two hundred and fifty breast cancer patients registered to use a portal providing access to personal health information over a six-week period. All support calls were directed to a research triage centre and redirected either to technical, clinical or psychosocial support. Log files

were coded and analyzed. Two hundred and thirty-nine support contacts were logged by 122 participants. The majority was referred to technical support; the remaining contacts were directed to clinical support. Seven categories of technical support were identified: registration problems, site access, login issues, password reset, activation key issues, result access and other difficulties. In accessing their test results, patients required support in a number of technical domains, but educational and psychosocial support were not heavily utilized.

Witry, M. J., Doucette, W. R., Daly, J. M., Levy, B. T., & Chrischilles, E. A. (2010). Family physician perceptions of personal health records. *Perspectives in Health Information Management, 7*, 1d.

The purpose of this qualitative study was to examine family practice physician and staff views on the benefits of, barriers to, and use of personal health records (PHRs). Four focus groups were conducted at four family medicine practices in Iowa and included a total of 28 providers. Overall, participants seemed to view PHRs as a source of medical information for healthcare providers when the patient's medical record is not available. Providers appeared unaware of the patient-centered features available in many electronic PHRs and how such features might affect patients and their medical practice. While physicians identified numerous patient groups that could benefit from using PHRs, they also perceived several unique barriers, including the potential of PHRs to facilitate narcotic abuse, low levels of patient computer and health literacy, low levels of patient motivation, and difficulties with PHR and electronic medical record interoperability. Physicians' relatively narrow view of PHR functions and

benefits and perception of barriers to using PHRs may restrict widespread support of PHR use.

Wynia, M., & Dunn, K. (2010). Dreams and nightmares: Practical and ethical issues for patients and physicians using personal health records. *Journal of Law, Medicine & Ethics*, 38(1), 64-73. doi:10.1111/j.1748-720X.2010.00467.x

Electronic health records for patients, personal health records (PHRs), have become increasingly popular among policy makers and purchasers, but uptake among patients and physicians has been relatively slow. PHRs have varying uses that might make them more or less appealing to different stakeholders. The three core uses for PHRs - promoting communication, data use, and patient responsibility - each raises a set of potential practical and financial dilemmas. But some ethical concerns are also at play, some of which are rarely recognized as values-based barriers to the use of PHRs. Recognizing these ethical issues, and addressing them explicitly in PHR design and policy making, would help PHRs to achieve their promise.

Yau, G. L., Williams, A. S., & Brown, J. B. (2011). Family physicians' perspectives on personal health records: qualitative study. *Canadian Family Physician*, 57(5), e178-84.

OBJECTIVE: To explore FPs' perspectives on the value of personal health records (PHRs) in primary care and the implementation and adoption of PHRs in Canada.

DESIGN: A qualitative design using semistructured interviews. SETTING: Southwestern Ontario. PARTICIPANTS: Ten FPs. METHODS: The 10 FPs participated in semistructured interviews, which were audiotaped and transcribed verbatim. An iterative approach using immersion and crystallization was employed for analysis.

MAIN FINDINGS: Participants were generally positive about PHRs, and were attracted to their portability and potential to engage patients in health care. Their concerns focused on 3 main themes: data management, practice management, and the patient-physician relationship. Subthemes included security, privacy, reliability of data, workload, remuneration, physician obligations, patient misinterpretation of medical information, and electronic communication displacing face-to-face visits. Participants identified 3 key facilitators for adoption of PHR systems: integration with existing electronic health record systems, ease of use without being a burden on either time or money, and offering a demonstrated added value to family practice. CONCLUSION: This study replicates previously published literature about FP concerns and opinions, and it further identifies remuneration as a potential barrier in Canadian fee-for-service payment models. Participants identified 3 key facilitators, which were suggested for implementation and adoption of PHRs, providing a basis for future research and development of these systems for use in Canadian family practice.

Benefits – Annotated Bibliography

Ahmadi, M., Jeddi, F. R., Gohari, M. R., & Sadoughi, F. (2012). A review of the personal health records in selected countries and Iran. *Journal of Medical Systems*, 36(2), 371-82.
doi:10.1007/s10916-010-9482-3

Personal Health Record (PHR) enables patients to access their health information and improves care quality by supporting self-care. The purpose of this study is to provide a comparative analysis of the concept of PHRs in selected countries and Iran in order to investigate the gaps between Iran and more advanced countries in terms of PHRs. The study was carried out in 2008-2009 using a descriptive-comparative method in Australia, the United States, England and Iran. Data was gathered from articles, books, journals and reputed websites in English and Persian published between 1995 and September 2009. After collecting the data, both advantages and disadvantages of each of concepts were analyzed. In the three countries considered in the present study the concepts of PHR, extracted from the literature, are that; a) patient/person be recognized as the owner of PHR; b) information be disclosed only to those authorized by the patient; c) and that PHR is created upon request and consent of the individual involved. Before PHRs can be profitably used in the health administration of a (developing) country, the necessary knowledge, infrastructures, and rules need to be developed.

Allison, M. (2009). Can web 2.0 reboot clinical trials? *Nature Biotechnology*, 27(10), 895-902. doi:10.1038/nbt1009-895

Dozens of companies are trying to leverage social networking and other software tools to accelerate trials and reduce their cost.

American Health Information Management Association, & American Medical Informatics Association. (2008). The value of personal health records. A joint position statement for consumers of health care. *Studies in Health Technology and Informatics*, 137, 402-405.

“The American Health Information Management Association (AHIMA) and the American Medical Informatics Association (AMIA) advocate empowering individuals to manage their healthcare through the use of a personal health record (PHR). The PHR is a tool for collecting, tracking and sharing important, up-to-date, information about an individual’s health or the health of someone in their care. Using a PHR will help people make better health decisions and improves quality of care by allowing them to access and use information needed to communicate effectively with others about their healthcare” (AHIMA).

The AHIMA and AMIA encourage consumers to begin tracking their health information in whatever format works best for the consumer, even if the method of tracking is paper. However, electronic media is recommended for a timely, accurate, and secure exchange of information.

“The American Health Information Management Association (AHIMA) and the American Medical Informatics Association (AMIA) advocate empowering individuals to manage their healthcare through the use of a personal health record (PHR). The PHR is a tool for collecting, tracking and sharing important, up-to-date, information about an individual’s health or the health of someone in their care. Using a PHR will help people

make better health decisions and improves quality of care by allowing them to access and use information needed to communicate effectively with others about their healthcare” (AHIMA).

Arrieta, M. I., Foreman, R. D., Crook, E. D., & Icenogle, M. L. (2009). Providing continuity of care for chronic diseases in the aftermath of Katrina: from field experience to policy recommendations. *Disaster Medicine and Public Health Preparedness*, 3(3), 174-182. doi:10.1097/DMP.0b013e3181b66ae4

This study sought to elicit challenges and solutions in the provision of health care to those with chronic diseases after Hurricane Katrina in coastal Alabama and Mississippi. In-depth interviews with 30 health and social service providers (key informants) and 4 focus groups with patients with chronic diseases were conducted. Subsequently an advisory panel of key informants was convened. Findings were summarized and key informants submitted additional feedback. The chronic diseases identified as medical management priorities by key informants were mental health, diabetes mellitus, hypertension, respiratory illness, end-stage renal disease, cardiovascular disease, and cancer. The most frequently mentioned barrier to providing care was maintaining continuity of medications. Contributing factors were inadequate information (inaccessible medical records, poor patient knowledge) and financial constraints. Implemented or suggested solutions included relaxation of insurance limitations preventing advance prescription refills; better predisaster patient education to improve medical knowledge; promotion of personal health records; support for information technology systems at community health centers, in particular electronic medical records; improved allocation of donated

medications/medical supplies (centralized coordination, decentralized distribution); and networking between local responders and external aid.

Balas, E. A., Krishna, S., & Tessema, T. A. (2008). eHealth: Connecting health care and public health. *Studies in Health Technology and Informatics*, 134, 169-176.

Reducing risks and improving benefits to the patients are requirements health professionals are faced with in their daily work. Furthermore, cuts in health funds and the competition for budgets require to enhancing efficacy and efficiency of health services. For meeting both challenges, adequate information and knowledge is needed, which can be gathered from documentation systems such as Electronic Health Records or Personal Health Records (PHRs), but also by performing dedicated clinical studies such as randomized controlled trials (RCTs) or cohort studies. Based on a literature analysis, quality of, and benefits from, RCTs have been analyzed. The benefits from connecting public health and PHRs are discussed in some details.

Ball, M. J., Costin, M. Y., & Lehmann, C. (2008). The personal health record: Consumers banking on their health. *Studies in Health Technology and Informatics*, 134, 35-46.

With personal health records (PHRs) acting much like ATM cards, increasingly wired consumers can "bank on health", accessing their own personal health information and a wide array of services. Consumer-owned, the PHR is dependent upon the existence of the legal electronic medical record (EMR) and interoperability. Working PHRs are in place in Veterans Health Administration, private health care institutions, and in the commercial sector. By allowing consumers to become involved in their own care, the PHR creates new roles and relationships. New tools change the clinician's workflow

and thought flow, and pose new challenges for consumers. Key components of the PHR include the EMR and regional health information organizations (RHIOs); key strategies focus on human factors in successful project management. Online resources provided by the National Library of Medicine and Health On the Net help address consumer needs for information that is reliable and understandable. The growth of self-management tools adds to the challenge and the promise of PHRs for clinicians and consumers alike.

Ball, M. J., & Gold, J. (2006). Banking on health: Personal records and information exchange. *Journal of Healthcare Information Management*, 20(2), 71-83.

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

Benhamou, P. Y. (2011). Improving diabetes management with electronic health records and patients' health records. *Diabetes & Metabolism*, 37 Suppl 4(Suppl 4), S53-6.

doi:10.1016/S1262-3636(11)70966-1

The lack of patient engagement and clinical inertia both contribute to suboptimal diabetes care. However, both obstacles are amenable to informatics- and Internet-based interventions. The use of electronic medical records (EMRs) is now established as being useful for improving diabetes care. Intelligent records that integrate computerized decision-support systems are now able to recommend care protocols tailored to risk levels. Web-based personal health record (PHR) systems, shared with healthcare providers, could also provide added value by promoting self-management of the behaviours related to diabetes. These Web-based programmes include patients' access to EMRs, uploading of glucose monitoring results, a glucose diary, secure e-mail with providers, manual or automated feedback on blood glucose readings and other risk factors, an educational website, and an online diary for entering personal information on exercise, diet and medication. The integration of Web-based patients' systems into the EMR used by physicians is the next frontier. In addition, the input from "smartphones" that are able to provide real-time support to patients could contribute to the reorganization of diabetes care. Convincing data on HbA(1c) improvements with such systems are available for type 2 diabetes, but are still equivocal for type 1 diabetes. Obstacles include patients' compliance with the technology, their ergonomic design and the need to reimburse providers for their care. Designing appropriate electronic tools and tailoring them to the conditions in France merits our attention.

Berry, J. G., Goldmann, D. A., Mandl, K. D., Putney, H., Helm, D., O'Brien, J., . . . Weinick, R. M. (2011). Health information management and perceptions of the quality of care for

children with tracheotomy: A qualitative study. *BMC Health Services Research*, 11, 117.

doi:10.1186/1472-6963-11-117

BACKGROUND: Children with tracheotomy receive health care from an array of providers within various hospital and community health system sectors. Previous studies have highlighted substandard health information exchange between families and these sectors. The aim of this study was to investigate the perceptions and experiences of parents and providers with regard to health information management, care plan development and coordination for children with tracheotomy, and strategies to improve health information management for these children. **METHODS:** Individual and group interviews were performed with eight parents and fifteen healthcare (primary and specialty care, nursing, therapist, equipment) providers of children with tracheotomy. The primary tracheotomy-associated diagnoses for the children were neuromuscular impairment (n = 3), airway anomaly (n = 2) and chronic lung disease (n = 3). Two independent reviewers conducted deep reading and line-by-line coding of all transcribed interviews to discover themes associated with the objectives. **RESULTS:** Children with tracheotomy in this study had healthcare providers with poorly defined roles and responsibilities who did not actively communicate with one another. Providers were often unsure where to find documentation relating to a child's tracheotomy equipment settings and home nursing orders, and perceived that these situations contributed to medical errors and delayed equipment needs. Parents created a home record that was shared with multiple providers to track the care that their children received but many considered this a burden better suited to providers. Providers benefited from the parent records, but questioned their accuracy regarding

critical tracheotomy care plan information such as ventilator settings. Parents and providers endorsed potential improvement in this environment such as a comprehensive internet-based health record that could be shared among parents and providers, and between various clinical sites. CONCLUSIONS: Participants described disorganized tracheotomy care and health information mismanagement that could help guide future investigations into the impact of improved health information systems for children with tracheotomy. Strategies with the potential to improve tracheotomy care delivery could include defined roles and responsibilities for tracheotomy providers, and improved organization and parent support for maintenance of home-based tracheotomy records with web-based software applications, personal health record platforms and health record data authentication techniques.

Bonander, J., & Gates, S. (2010). Public health in an era of personal health records: Opportunities for innovation and new partnerships. *Journal of Medical Internet Research*, 12(3), e33. doi:10.2196/jmir.1346

In the near future, citizens will be able to control and manage their own health information through electronic personal health record systems and tools. The clinical benefits of this innovation, such as cost savings, error reduction, and improved communication, have been discussed in the literature and public forums, as have issues related to privacy and confidentiality. Receiving little attention are the benefits these will have for public health. The benefits and potential for innovation are broad and speak directly to core public health functions such as health monitoring, outbreak management, empowerment, linking to services, and research. Coupled with this is a

new relationship with citizens as key partners in protecting and promoting the public's health.

Dorr, D., Bonner, L. M., Cohen, A. N., Shoai, R. S., Perrin, R., Chaney, E., & Young, A. S. (2007).

Informatics systems to promote improved care for chronic illness: A literature review. *Journal of the American Medical Informatics Association*, 14(2), 156-163.

doi:10.1197/jamia.M2255

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

a positive impact of specific health information technology components on chronic illness care. Implications for future research and system designs are discussed.

Endsley, S., Kibbe, D. C., Linares, A., & Colorafi, K. (2006). An introduction to personal health records. *Family Practice Management, 13*(5), 57-62.

The author provides a patient story to exemplify the importance of a PHR. Three visions/ definitions of a PHR are then provided. One version of personal health records is a provider-owned digital summary that patients can access but cannot change. A second definition is a patient-owned program patients can use to enter and organize their health information. The third version is a portable digital file that can be transferred between computers and that corresponds closely to the Continuity of Care Record (CCR) standard. It includes a listing of the main elements of the CCR.

Grant, R. W., Wald, J. S., Schnipper, J. L., Gandhi, T. K., Poon, E. G., Orav, E. J., . . . Middleton, B. (2008). Practice-linked online personal health records for type 2 diabetes mellitus: a randomized controlled trial. *Archives of Internal Medicine, 168*(16), 1776-1782.
doi:10.1001/archinte.168.16.1776

BACKGROUND: Web-based personal health records (PHRs) have been advocated as a means to improve type 2 diabetes mellitus (DM) care. However, few Web-based systems are linked directly to the electronic medical record (EMR) used by physicians.

METHODS: We randomized 11 primary care practices. Intervention practices received access to a DM-specific PHR that imported clinical and medications data, provided patient-tailored decision support, and enabled the patient to author a "Diabetes Care Plan" for electronic submission to their physician prior to upcoming appointments.

Active control practices received a PHR to update and submit family history and health maintenance information. All patients attending these practices were encouraged to sign up for online access. RESULTS: We enrolled 244 patients with DM (37% of the eligible population with registered online access, 4% of the overall population of patients with DM). Study participants were younger (mean age, 56.1 years vs 60.3 years; $P < .001$) and lived in higher-income neighborhoods (median income, \$53,784 vs \$49,713; $P < .001$) but had similar baseline glycemic control compared with nonparticipants. More patients in the intervention arm had their DM treatment regimens adjusted (53% vs 15%; $P < .001$) compared with active controls. However, there were no significant differences in risk factor control between study arms after 1 year ($P = .53$). CONCLUSIONS: Previsit use of online PHR linked to the EMR increased rates of DM-related medication adjustment. Low rates of online patient account registration and good baseline control among participants limited the intervention's impact on overall risk factor control. TRIAL REGISTRATION: clinicaltrials.gov Identifier: NCT00251875.

Kaelber, D., & Pan, E. C. (2008). The value of personal health record (PHR) systems. *AMIA Annual Symposium Proceedings, 2008*, 343-347.

Personal health records (PHRs) are a rapidly growing area of health information technology despite a lack of significant value-based assessment. Here we present an assessment of the potential value of PHR systems, looking at both costs and benefits. We examine provider-tethered, payer-tethered, and third-party PHRs, as well as idealized interoperable PHRs. An analytical model was developed that considered eight PHR application and infrastructure functions. Our analysis projects the initial and

annual costs and annual benefits of PHRs to the entire US over the next 10 years. This PHR analysis shows that all forms of PHRs have initial net negative value. However, at the end of 10 years, steady state annual net value ranging from \$13 billion to -\$29 billion. Interoperable PHRs provide the most value, followed by third-party PHRs and payer-tethered PHRs also showing positive net value. Provider-tethered PHRs constantly demonstrating negative net value.

Kahn, S., & Hickner, J. (2009). *A community view: How personal health records can improve patient care and outcomes in many health care settings*. Retrieved April 22, 2011, from http://www.niu.edu/rdi/pdf/personal_health_records_and_patient_care_2009.pdf

This series of essays on personal health records is the result of collaboration between two Illinois organizations: Northern Illinois Physicians for Connectivity and the Chicago Patient Safety Forum. Together, the two organizations brought together healthcare providers, healthcare administrators, insurers, and technology visionaries in the Chicago Metropolitan area through a series of educational and planning meetings in 2007 and 2008 to discuss ways to improve patient safety in Illinois through the use of healthcare information technology. Over time, one issue that emerged as a top priority from a community perspective was a consumer-centered approach to healthcare based on the use of personal health records. The essays in this monograph arose from those discussions. They aim to raise awareness and lower uncertainty about the benefits of personal health records (PHRs) among all stakeholders in Illinois, including consumers of healthcare, healthcare providers, purchasers of healthcare, and policy makers. By increasing

general knowledge about their incredible potential to improve the quality and safety of healthcare, we hope to accelerate the adoption of personal health records. Usability is another important factor in increasing technology adoption. Throughout these essays, we have included specific examples of uses of PHRs. There are eleven perspectives covered by this document: Private Practice Providers, Academic Providers, Private Hospitals, Integrated Delivery System Providers, Federally Qualified Health Clinic, Long-Term Care Facilities, Pharmacists, Nurses, Consumers, Rural Healthcare Providers, and Employee Benefits. There are three technical essays: Privacy and security of PHRs, Technical aspects of linking PHRs electronically to EHRs, and Technical challenges unique to persons with disabilities

Kupchunas, W. R. (2007). Personal health record: New opportunity for patient education. *Orthopaedic Nursing*, 26(3), 185-91.

doi:10.1097/01.NOR.0000276971.86937.c4

The personal health record (PHR) allows individuals to keep track of their health care information in one location. Maintaining a PHR encourages increased personal participation in healthcare and fosters a greater emphasis on communication between the individual and the caregivers. The creation of a PHR provides the opportunity for health professionals to educate patients about personal health matters and presents a tool for enhancing health literacy. As patients become more adept at communicating with their caregivers and recording important health information, the ability to participate in decision making is enhanced. Assessment of health literacy and functional ability allows the PHR to be adapted to accommodate the needs of the individual. Identification of family members or other significant individuals early on is

essential, and education efforts should begin promptly. This article provides information on the benefits of a PHR. Considerations for health literacy and ability to maintain a PHR are discussed, and examples of using a transdisciplinary approach to development and implementation of a PHR are examined. With proper design and education, the PHR allows individuals to participate more fully in their own healthcare.

Luckmann, R., & Vidal, A. (2010). Design of a handheld electronic pain, treatment and activity diary. *Journal of Biomedical Informatics*, 43(5 Suppl), S32-6.

doi:10.1016/j.jbi.2010.05.005

Effective tools for recording and analyzing data on patients' pain experience, use of pain treatments, and physical function are needed to improve communication between providers and patients with noncancer chronic pain. A handheld electronic diary (HED) that can be used throughout the day may provide more useful and accurate information about pain, treatments, and function than available paper and on-line diaries that are designed to be used once daily, weekly or less often. Based on user-specified requirements we designed and built a prototype HED with 7 modules. Diary queries are followed by multiple choice responses customized to the patients' expected responses. Usability testing confirmed user comprehension and acceptability of the queries, response sets, and interface.

New-age PHR comes with decision-support, multiple opportunities for DM. (2006). *Disease Management Advisor*, 12(12), 140-2, 133.

New-age PHRs aim to uncover opportunities for quality improvement. Health plans have been scrutinizing administrative data for years, but thus far have not offered such

analysis to patients or providers. Doing so is just part of the package that will soon be made available to the customers of Manhattan, NY-based ActiveHealth Management through Web-based personal health records. The approach is designed to get patients more involved in their own care, facilitating analysis of not just claims data, but patient-reported data as well.

Oftedahl, G., & Marshall, M. (2010). The future of personal health records: A summary of a roundtable discussion. *Minnesota Medicine*, 93(7), 50-52. Retrieved from <http://www.minnesotamedicine.com/PastIssues/PastIssues2010/July2010/ClinicalOftedahlJuly2010.aspx>

In 2009, the Institute for Clinical Systems Improvement held a roundtable on personal health records (PHRs). Participants shared their thoughts about which features and functions are desired in a PHR, areas that need further exploration, and ways PHRs could make health care more efficient and effective. This article summarizes those discussions.

Raisinghani, M. S., & Young, E. (2008). Personal health records: key adoption issues and implications for management. *International Journal of Electronic Healthcare*, 4(1), 67-77.

Electronic Personal Health Records (PHRs) has been perceived as the tool to empower consumers to become active decision-makers of their healthcare instead of leaving the decision to providers. However, there has been the lack of enthusiasm and adoption of PHRs. This paper examines the current healthcare climate and attempts to understand the major challenges associated with PHRs adoption. The paper-based and fragmented

healthcare system is no longer appropriate for the digital economy of the 21st century. The integrated health information technology system is the solution to transform clinical practice to consumer centric and information driven. Tools such as PHRs are means to an end that provide better, safer and more affordable healthcare for consumers. However, there has been little research conducted to demonstrate PHR's tangible value, despite the widespread perceived value of these technologies. Although survey data reveals that there is a lack of awareness among the public, consumers are receptive to this concept, especially when a physician recommends it. Key issues in adopting PHRs and strategies for successful implementation of PHRs are discussed.

Reti, S. R., Feldman, H. J., Ross, S. E., & Safran, C. (2010). Improving personal health records for patient-centered care. *Journal of the American Medical Informatics Association*, 17(2), 192-195. doi:10.1136/jamia.2009.000927

OBJECTIVE: To assess the patient-centeredness of personal health records (PHR) and offer recommendations for best practice guidelines. DESIGN: Semi-structured interviews were conducted in seven large early PHR adopter organizations in 2007. Organizations were purposively selected to represent a variety of US settings, including medium and large hospitals, ambulatory care facilities, insurers and health plans, government departments, and commercial sectors. MEASUREMENTS: 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; (8) coordination of care. Within this framework we used

evidence for patient preferences (where it exists) to compare existing PHR policies, and propose a best practice model. RESULTS: 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. CONCLUSION: Findings suggest patient-centeredness for personal health records can be improved, and recommendations are made for best practice guidelines.

Samoocha, D., Bruinvels, D. J., Anema, J. R., Steenbeek, R., & van der Beek, A. J. (2009).

Empowerment of disability benefit claimants through an interactive website: Design of a randomized controlled trial. *BMC Medical Informatics and Decision Making*, 9, 23.

doi:10.1186/1472-6947-9-23

BACKGROUND: Individuals claiming a disability benefit after long-term sickness absence, have to undergo medical disability assessments. These assessments, often carried out by specialized physicians, can be complicated by wrong expectations or defensive attitudes of disability benefit claimants. It is hypothesized that empowerment of these claimants will enhance the physician-patient relationship by shifting claimants from a passive role to a more active and constructive role during disability assessments. Furthermore, empowerment of claimants may lead to a more realistic expectation and acceptance of the assessment outcome among claimants and may lead to a more accurate assessment by the physician. METHODS/DESIGN: In a two-armed randomized controlled trial (RCT), 230 claimants will be randomized to either the intervention or control group. For the intervention group, an interactive website was designed <http://www.wiagesprek.nl> using an Intervention Mapping

procedure. This website was tested during a pilot study among 51 claimants. The final version of the website consists of five interactive modules, in which claimants will be prepared and empowered step-by-step, prior to their upcoming disability assessment. Other website components are a forum, a personal health record, a personal diary, and information on disability assessment procedures, return to work, and coping with disease and work disability. Subjects from the control group will be directed to a website with commonly available information only. Approximately two weeks prior to their disability assessment, disability claimants will be recruited through the Dutch Workers Insurance Authority (UWV). Outcomes will be assessed at five occasions: directly after recruitment (baseline), prior to disability assessment, directly after disability assessment as well as 6 and 16 weeks after the assessment. The study's primary outcome is empowerment, measured with the Vrijbaan questionnaire. Secondary outcomes include claimants' satisfaction, perceived justice, coping strategy, and knowledge. A process evaluation will also be conducted. DISCUSSION: This study evaluates the effectiveness of an interactive website aimed at empowerment of disability claimants. It is hypothesized that by increasing empowerment, the physician-patient relationship may be enhanced and claimants' satisfaction and perceived justice can be improved. Results are expected in 2010. TRIAL REGISTRATION: NTR-1414.

Sensmeier, J., & Casey Halley, E. (2009). Connecting humans and health through health information exchange. *Studies in Health Technology and Informatics*, 146, 756-757.

To address healthcare quality, efficiency and safety, a national health information technology (IT) initiative was announced by the President of the United States in 2004 to make Electronic Health Records (EHR) available to most Americans within 10 years.

The National Health IT Agenda has advanced with recognition of interoperability standards for Personal Health Records (PHR) and Population Health information exchange. This session will illustrate the national processes, timeline, stakeholders and benefits of adoption of interoperability standards to enable health information exchange.

Sequist, T. D., Zaslavsky, A. M., Colditz, G. A., & Ayanian, J. Z. (2011). Electronic patient messages to promote colorectal cancer screening: A randomized controlled trial. *Archives of Internal Medicine*, 171(7), 636-641.

doi:10.1001/archinternmed.2010.467

BACKGROUND: Colorectal cancer is a leading cause of cancer mortality, yet effective screening tests are often underused. Electronic patient messages and personalized risk assessments delivered via an electronic personal health record could increase screening rates. **METHODS:** We conducted a randomized controlled trial in 14 ambulatory health centers involving 1103 patients ranging in age from 50 to 75 years with an active electronic personal health record who were overdue for colorectal cancer screening. Patients were randomly assigned to receive a single electronic message highlighting overdue screening status with a link to a Web-based tool to assess their personal risk of colorectal cancer. The outcomes included colorectal cancer screening rates at 1 and 4 months. **RESULTS:** Screening rates were higher at 1 month for patients who received electronic messages than for those who did not (8.3% vs 0.2%, $P < .001$), but this difference was no longer significant at 4 months (15.8% vs 13.1%, $P = .18$). Of 552 patients randomized to receive the intervention, 296 (54%) viewed the message, and 47 (9%) used the Web-based risk assessment tool. Among

296 intervention patients who viewed the electronic message, risk tool users were more likely than nonusers to request screening examinations (17% vs 4%, $P = .04$) and to be screened (30% vs 15%, $P = .06$). One-fifth of patients (19%) using the risk assessment tool were estimated to have an above-average risk for colorectal cancer.

CONCLUSION: Electronic messages to patients produce an initial increase in colorectal cancer screening rates, but this effect is not sustained over time. **TRIAL**

REGISTRATION: clinicaltrials.gov Identifier: NCT01032746.

Stock, R., Mahoney, E. R., Gauthier, D., Center, L., Minniti, M., Scott, J., . . . Nichols, L. (2008).

Developing a community-wide electronic shared medication list. In K. Henriksen, J. B. Battles, M. A. Keyes & M. L. Grady (Eds.), *Advances in Patient Safety: New Directions and Alternative Approaches (Vol. 4: Technology and Medication Safety)* (). Rockville (MD):

This study demonstrates the feasibility of developing a medication list e-tool from multiple medication data sources that is accessible to patients, caregivers, and health care practices and is "portable" or accessible wherever patients go. A single medication list was created electronically by integrating data from the Shared Care Plan, a Web-based personal health record, and clinic electronic medical records (EMRs) to create a single, Web-based view. The feasibility of sharing accurate, updated information with everyone involved in a patient's care was explored using innovative technology and training, while motivating health care professionals and patients to communicate medication regimen changes. Qualitative and quantitative evaluation methodologies were utilized to assess the impact of interventions among three outpatient clinic sites and 108 adult patients. Through extensive collaboration, clinic sites improved the

accuracy of patient EMR medication lists, medication safety culture improved, and patients found the electronic medication list beneficial.

Tang, P. C., Ash, J. S., Bates, D. W., Overhage, J. M., & Sands, D. Z. (2006). Personal health records: Definitions, benefits, and strategies for overcoming barriers to adoption. *Journal of the American Medical Informatics Association*, 13(2), 121-126. doi:10.1197/jamia.M2025

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

Tang, P. C., & Lee, T. H. (2009). Your doctor's office or the Internet? Two paths to personal health records. *New England Journal of Medicine*, 360(13), 1276-1278.

doi:10.1056/NEJMp0810264

The authors provides a case study demonstrating the need for a PHR. They then go onto contrast the benefits of a stand alone vs tethered PHR. Tethered PHRs can offer patients as much access to data, scheduling resources, and communication among members of the health care team as providers are willing to permit. Users of integrated PHRs have demonstrated that creating shared records for patients and their health care team can enhance patients' ability to become active partners in their own health care.

Tani, S., Marukami, T., Matsuda, A., Shindo, A., Takemoto, K., & Inada, H. (2010).

Development of a health management support system for patients with diabetes mellitus at home. *Journal of Medical Systems*, 34(3), 223-228.

Recently, a patient with diabetes mellitus (DM) type 2 has been increasing in Japan. The patient should be managed not only by a specialist but also by himself focusing his attention on the improvement of his lifestyle at home. In the present study, we tried to develop a health management support system by which a diabetic patient in early stage can easily enter his daily life information, i.e. the biological information such as the data of blood sugar levels and blood pressure levels etc., the information of exercise and diet and send the information to the medical institution with a personal digital assistant (PDA). Afterwards, the patient can receive health instruction information by the physician in charge for self-care at his home with a PDA. The daily life information sent from the patient is stored in a server installed at the medical

institution and analyzed. The physician can obtain the results of analysis by using a PC and send the instruction information necessary for patient management to the patient at home by using e-mail after diagnosing the patient's condition by the system. To evaluate usability of the developed patient information input system with a PDA, an experiment was conducted by corporation of 20 volunteers who were possible self management and whose age's range from 20s to 60s by questionnaire survey. As a result, almost examinees answered that lifestyle information could be easily entered by the sense like a mobile-phone and lots of positive opinions were obtained.

Tenforde, M., Jain, A., & Hickner, J. (2011). The value of personal health records for chronic disease management: What do we know? *Family Medicine*, 43(5), 351-354.

BACKGROUND AND OBJECTIVES: Electronic personal health records (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, we explore the evidence for the value of PHRs in chronic disease management. **METHODS:** We used a comprehensive review of MEDLINE articles published in English between January 2000 and September 2010 on personal health records and related search terms. **RESULTS:** Few published articles have described PHR programs designed for use in chronic disease management or PHR adoption and attitudes in the context of chronic disease management. Only three prospective randomized trials have evaluated

the benefit of PHR use in chronic disease management, all in diabetes care. These trials showed small improvements in some but not all diabetes care measures. All three trials involved additional interventions, making it difficult to determine the influence of patient PHR use in improved outcomes. CONCLUSIONS: The evidence remains sparse to support the value of PHR use for chronic disease management. With the current policy focus on meaningful use of electronic and personal health records, it is crucial to investigate and learn from new PHR products so as to maximize the clinical value of this tool.

Tuil, W. S., Verhaak, C. M., Braat, D. D., de Vries Robbe, P. F., & Kremer, J. A. (2007).

Empowering patients undergoing in vitro fertilization by providing Internet access to medical data. *Fertility and Sterility*, 88(2), 361-368.

doi:10.1016/j.fertnstert.2006.11.197

OBJECTIVE: To study the effect of an Internet-based personal health record on the empowerment of patients undergoing IVF. DESIGN: Randomized clinical trial.

SETTING: Patients undergoing IVF and intracytoplasmic sperm injection (ICSI) in an academic research environment. PATIENT(S): We selected patients who were

undergoing an IVF or ICSI treatment, have an Internet connection, and speak fluent

Dutch. INTERVENTION(S): An Internet-based personal health record that provides

patients with general and personal information concerning their given treatment and that also provides facilities for communication with fellow patients and physicians.

MAIN OUTCOME MEASURE(S): Patient empowerment (measured as a

multidimensional concept consisting of self-efficacy, actual and perceived knowledge, and involvement in the decision process), patient satisfaction, meaning of infertility

problems, social support, anxiety, and depression. RESULT(S): A total of 91 female and 89 male participants were suitable for analysis. No significant differences were observed in per person change in patient empowerment. We did not find any significant differences regarding per person change in patient satisfaction, the meaning of infertility problems, social support, anxiety, and depression. CONCLUSION(S): Usage of the personal health record did not have any effects on patient empowerment, but, at the same time, the study did not find that the personal health record had any significant adverse effects either.

Turvey, C. L., Zulman, D. M., Nazi, K. M., Wakefield, B. J., Woods, S. S., Hogan, T. P., . . .

McInnes, K. (2012). Transfer of Information from Personal Health Records: A Survey of Veterans Using My HealtheVet. *Telemedicine Journal and e-Health*, doi:10.1089/tmj.2011.0109

Abstract Objective: Personal health records provide patients with ownership of their health information and allow them to share information with multiple healthcare providers. However, the usefulness of these records relies on patients understanding and using their records appropriately. My HealtheVet is a Web-based patient portal containing a personal health record administered by the Veterans Health Administration. The goal of this study was to explore veterans' interest and use of My HealtheVet to transfer and share information as well as to identify opportunities to increase veteran use of the My HealtheVet functions. Materials and Methods: Two waves of data were collected in 2010 through an American Customer Satisfaction Index Web-based survey. A random sample of veterans using My HealtheVet was invited to participate in the survey conducted on the My HealtheVet portal through a

Web-based pop-up browser window. Results: Wave One results (n=25,898) found that 41% of veterans reported printing information, 21% reported saving information electronically, and only 4% ever sent information from My HealtheVet to another person. In Wave Two (n=18,471), 30% reported self-entering medication information, with 18% sharing this information with their Veterans Affairs (VA) provider and 9.6% sharing with their non-VA provider. Conclusion: Although veterans are transferring important medical information from their personal health records, increased education and awareness are needed to increase use. Personal health records 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.

Valdiserri, R. O., Nazi, K., McInnes, D. K., Ross, D., & Kinsinger, L. (2010). Need to improve routine HIV testing of U.S. Veterans in care: Results of an Internet survey. *Journal of Community Health, 35*(3), 215-219. doi:10.1007/s10900-010-9233-x

Late diagnosis of HIV infection contributes to poor medical outcomes and helps sustain continued transmission of virus. Published evidence suggests that despite current public health recommendations, patients receiving care in the Veterans Health Administration (VHA) system are not being routinely tested for HIV infection. Using a sample of computer-literate veterans, we conducted a survey of recent testing experiences. My HealtheVet (MHV) is a secure website allowing registered Veterans to access limited personal VHA health information. Using the American Customer Satisfaction Index (ACSI) Survey, an electronic questionnaire on "health screening" was conducted in late Fall/early winter 2008-2009. A random sample (4%) of MHV

users were surveyed; approximately 17% completed the survey and responses ranged from 31,237 to 33,074. Only 9% of the respondents indicated that they had been offered a test for HIV in the last 12 months compared to 83% who had been offered cholesterol screening, 65% blood sugar screening and 19% who had been offered testing for Hepatitis C virus (HCV). Of those who had been offered HIV testing, 91% indicated that they'd had the test performed. Of note, the percentage of respondents who indicated that they would "very likely" accept a test, if offered, was similar for HIV (73%), HCV (79%), cholesterol (75%), and blood sugar (75%). Although these results cannot be generalized to all Veterans in care, they suggest that routine testing for HIV has not been taking place and support recent VHA policy changes to remove barriers to HIV testing.

Varroud-Vial, M. (2011). Improving diabetes management with electronic medical records. *Diabetes & Metabolism, 37 Suppl 4*(Suppl 4), S48-52. doi:10.1016/S1262-3636(11)70965-X

Most primary-care physicians have adopted electronic medical records (EMRs) for the management of patients in ambulatory care. Observational trials suggest that the use of EMRs improves the achievement of the recommended standards of diabetes care and intermediate outcomes. A French group of general practitioners has shown, in a randomized controlled trial of diabetes care, the beneficial effects of a follow-up module integrated into an EMR. Electronic reminders, eHealth technology and e-mail messaging to patients integrated into the EMR have also been reported to have a beneficial effect on diabetes care. Some recommendations have been devised for the meaningful use of EMRs to improve the process and, possibly, intermediate outcomes

of diabetes care as well. Another potential benefit to consider is the extraction and aggregation of data to create diabetes registers. Large regional and national diabetes registers have been set up in the US and Europe for various purposes, including patient recall, description of care patterns and outcomes, improvement of practices, drug safety, observational research and retrospective trials. In France, the government initiative towards an Internet-based personal health record (PHR) provides an appropriate framework for implementing and sharing the information needed to improve diabetes care, such as electronic summaries of health information, personalized health plans (PHPs), and standardized and structured hospital-discharge forms. All of these materials can be generated from EMRs. The widespread and optimized use of EMRs for diabetes care with links to the national diabetes register and the capacity to supply PHRs are major considerations. Achieving these goals requires a common initiative comprising primary care and diabetes scientific societies in cooperation with diabetes patients' associations.

VA's web-based personal health record can be a model for others. (2005). *Internet Healthcare Strategies*, 7(4), 8-10.

The VA is a leader in development of PHRs. In this article the pitfalls of not having a PHR demonstrate the benefits that a PHR can help overcome. Often patients don't tell their whole story and often most patients move. The web-based electronic world connects people and PHRs that are web-enabled to improve documentation and communication of personal health issues.

Wackerle, A., Blochlinger-Wegmann, B., Burkhardt, T., Krahenmann, F., Kurmanavicius, J., & Zimmermann, R. (2010). Notes on a stick: Use and acceptability of woman-held maternity notes. *European Journal of Obstetrics, Gynecology, and Reproductive Biology*, 153(2), 156-159. doi:10.1016/j.ejogrb.2010.07.019

OBJECTIVE: To provide expectant mothers with a USB stick containing their maternity notes, including ultrasound images, and to assess its use and acceptability versus conventional care with exclusively hospital-held notes. STUDY DESIGN: USB group: 200 women attending Zurich University Hospital Obstetrics Department for antenatal-to-postnatal care in 2006-2007. Controls: 200 women attending the Obstetrics Department for delivery only, after receiving conventional antenatal care elsewhere. Women were interviewed using an essentially identical postpartum questionnaire for each group, with minor wording differences. Main outcome measures: Overall satisfaction with pregnancy and delivery, feeling of safety, interest in the pregnancy, partner involvement, usefulness of USB stick in emergencies, impact on smoking behaviour, data confidentiality concerns, pregnancy and infant outcome. Stepwise multiple regression was used to identify determinants of overall impressions of pregnancy and delivery. RESULTS: Of the USB group, 98.5% wished to repeat the USB experience in a subsequent pregnancy; of the controls, 86.5% would have appreciated the experience, and 18.0% could think of situations in their pregnancy (vacation, emergencies) where the stick would have helped; 7.5% of the USB group shared their stick data with a doctor outside the Department, and 80.5% felt safer having the stick available. Along with preterm delivery and mode of delivery, the USB stick was a significant determinant of the overall positive impression of pregnancy. Primary

caesarean section was (inexplicably) more frequent in the USB group. CONCLUSION:
The questionnaire confirmed that issuing women with their maternity notes on a USB
stick is a major advance in patient empowerment, satisfaction and safety.

Wagner, P. J., Dias, J., Howard, S., Kintziger, K. W., Hudson, M. F., Seol, Y. H., & Sodomka, P.
(2012). Personal health records and hypertension control: A randomized trial. *Journal
of the American Medical Informatics Association*, 2012 Jan 12, Epub ahead of print.
doi:10.1136/amiajnl-2011-000349

Purpose: To examine the impact of a personal health record (PHR) in patients with
hypertension measured by changes in biological outcomes, patient empowerment,
patient perception of quality of care, and use of medical services. Methods A cluster-
randomized effectiveness trial with PHR and no PHR groups was conducted in two
ambulatory clinics. 453 of 1686 (26.4%) patients approached were included in the
analyses. A PHR tethered to the patient's electronic medical record (EMR) was the
primary intervention and included security measures, patient control of access, limited
transmission of EMR data, blood pressure (BP) tracking, and appointment assistance.
BP was the main outcome measure. Patient empowerment was assessed using the
Patient Activation Measure and Patient Empowerment Scale. Quality of care was
assessed using the Clinician and Group Assessment Score (CAHPS) and the Patient
Assessment of Chronic Illness Care. Frequency of use of medical services was self-
reported. Results No impact of the PHR was observed on BP, patient activation, patient
perceived quality, or medical utilization in the intention-to-treat analysis. Sub-analysis
of intervention patients self-identified as active PHR users (25.7% of those with
available information) showed a 5.25-point reduction in diastolic BP. Younger age, self-

reported computer skills, and more positive provider communication ratings were associated with frequency of PHR use. Conclusions Few patients provided with a PHR actually used the PHR with any frequency. Thus simply providing a PHR may have limited impact on patient BP, empowerment, satisfaction with care, or use of health services without additional education or clinical intervention designed to increase PHR use. Clinical trial registration number <http://ClinicalTrials.gov> Identifier: NCT01317537.

What doctors wish their patients knew: Surprising results from our survey of 660 primary-care physicians. (2011). *Consumer Reports*, 76(3), 20-23.

The article is a report of 660 primary-care physicians who described professional challenges and what patients could do to get more out of their relationship with their physician. Some highlights of the surveys: 1) Doctors and patients alike put a high value on courtesy and professionalism, 3) Patients aren't taking full advantage of strategies that doctors think are helpful such as taking notes during their visits, and 3) Not knowing much up front about a doctor's personality or treatment style was a real obstacle for patients in search of a good match.

Wilcox, A., Natarajan, K., & Weng, C. (2009). Using personal health records for automated clinical trials recruitment: The ePaIRing model. *Summit on Translational Bioinformatics, 2009*, 136-140.

We describe the development of a model describing the use of patient information to improve patient recruitment in clinical trials. This model, named ePaIRing (electronic Participant Identification and Recruitment Model) describes variations in how

information flows between stakeholders, and how personal health records can specifically facilitate patient recruitment.

Wiler, J. L., Gentle, C., Halfpenny, J. M., Heins, A., Mehrotra, A., Mikhail, M. G., & Fite, D.

(2010). Optimizing emergency department front-end operations. *Annals of Emergency Medicine*, 55(2), 142-160.e1. doi:10.1016/j.annemergmed.2009.05.021

As administrators evaluate potential approaches to improve cost, quality, and throughput efficiencies in the emergency department (ED), "front-end" operations become an important area of focus. Interventions such as immediate bedding, bedside registration, advanced triage (triage-based care) protocols, physician/practitioner at triage, dedicated "fast track" service line, tracking systems and whiteboards, wireless communication devices, kiosk self check-in, and personal health record technology ("smart cards") have been offered as potential solutions to streamline the front-end processing of ED patients, which becomes crucial during periods of full capacity, crowding, and surges. Although each of these operational improvement strategies has been described in the lay literature, various reports exist in the academic literature about their effect on front-end operations. In this report, we present a review of the current body of academic literature, with the goal of identifying select high-impact front-end operational improvement solutions.

Wiljer, D., Leonard, K. J., Urowitz, S., Apatu, E., Massey, C., Quartey, N. K., & Catton, P. (2010).

The anxious wait: Assessing the impact of patient accessible EHRs for breast cancer patients. *BMC Medical Informatics and Decision Making*, 10, 46. doi:10.1186/1472-6947-10-46

BACKGROUND: Personal health records (PHRs) provide patients with access to personal health information (PHI) and targeted education. The use of PHRs has the potential to improve a wide range of outcomes, including empowering patients to be more active participants in their care. There are a number of widespread barriers to adoption, including privacy and security considerations. In addition, there are clinical concerns that patients could become anxious or distressed when accessing complex medical information. This study assesses the implementation of a PHR, and its impact on anxiety levels and perceptions of self-efficacy in a sample of breast cancer patients.

METHODS: A quasi-experimental pre-test/post-test design was used to collect data from participants to evaluate the use of the PHR. Study participants completed background and pre-assessment questionnaires and were then registered into the portal. By entering an activation key, participants were then able to review their lab results and diagnostic imaging reports. After six weeks, participants completed post-assessment questionnaires and usability heuristics. All data were collected using an online survey tool. Data were cleaned and analyzed using SAS v9.1.

RESULTS: A total of 311 breast cancer patients completed demographic and pre-assessment questionnaires, 250 registered to use the online intervention, and 125 participants completed all required study elements. Matching the pre- and post-anxiety scores demonstrated a decrease in mean anxiety scores (-2.2, $p = 0.03$); the chemotherapy sub-group had a statistically insignificant mean increase (1.8, $p = .14$). There was no mean change in self-efficacy scores.

CONCLUSIONS: Participants generally found the portal easy to use; however, the perceived value of improved participation was not detected in the self-efficacy scores. Having access to personal health information did

not increase anxiety levels. While these results suggest that the use of this PHR may be of benefit for informing patients, further research is required to investigate the impact on the patients experiences, their participation in their care, their relationships with the health care team, and their health outcomes.

Witry, M. J., Doucette, W. R., Daly, J. M., Levy, B. T., & Chrischilles, E. A. (2010). Family physician perceptions of personal health records. *Perspectives in Health Information Management, 7*, 1d.

The purpose of this qualitative study was to examine family practice physician and staff views on the benefits of, barriers to, and use of personal health records (PHRs). Four focus groups were conducted at four family medicine practices in Iowa and included a total of 28 providers. Overall, participants seemed to view PHRs as a source of medical information for healthcare providers when the patient's medical record is not available. Providers appeared unaware of the patient-centered features available in many electronic PHRs and how such features might affect patients and their medical practice. While physicians identified numerous patient groups that could benefit from using PHRs, they also perceived several unique barriers, including the potential of PHRs to facilitate narcotic abuse, low levels of patient computer and health literacy, low levels of patient motivation, and difficulties with PHR and electronic medical record interoperability. Physicians' relatively narrow view of PHR functions and benefits and perception of barriers to using PHRs may restrict widespread support of PHR use.

Wolter, J., & Friedman, B. (2005). Health records for the people. Touting the benefits of the consumer-based personal health record. *Journal of AHIMA*, 76(10), 28-32.

This article includes benefits of PHRs are then described. Patients who track their health care through a PHR can provide useful information to their provider, such as a list of medications, the reason for taking particular medications, and other health treatments. Having an accurate health history, particularly for patients who travel or have care from more than one provider, can avoid duplicate tests, delayed treatments, and compromised care. The article describes various types of PHRs.

Wright, A., Poon, E. G., Wald, J., Feblowitz, J., Pang, J. E., Schnipper, J. L., . . . Middleton, B.

(2012). Randomized controlled trial of health maintenance reminders provided directly to patients through an electronic PHR. *Journal of General Internal Medicine*, 27(1), 85-92. doi:10.1007/s11606-011-1859-6

BACKGROUND: Provider and patient reminders can be effective in increasing rates of preventive screenings and vaccinations. However, the effect of patient-directed electronic reminders is understudied. OBJECTIVE: To determine whether providing reminders directly to patients via an electronic Personal Health Record (PHR) improved adherence to care recommendations. DESIGN: We conducted a cluster randomized trial without blinding from 2005 to 2007 at 11 primary care practices in the Partners HealthCare system. PARTICIPANTS: A total of 21,533 patients with access to a PHR were invited to the study, and 3,979 (18.5%) consented to enroll.

INTERVENTIONS: Patients in the intervention arm received health maintenance (HM) reminders via a secure PHR "eJournal," which allowed them to review and update HM and family history information. Patients in the active control arm received access to an

eJournal that allowed them to input and review information related to medications, allergies and diabetes management. MAIN MEASURES: The primary outcome measure was adherence to guideline-based care recommendations. KEY RESULTS: Intention-to-treat analysis showed that patients in the intervention arm were significantly more likely to receive mammography (48.6% vs 29.5%, $p = 0.006$) and influenza vaccinations (22.0% vs 14.0%, $p = 0.018$). No significant improvement was observed in rates of other screenings. Although Pap smear completion rates were higher in the intervention arm (41.0% vs 10.4%, $p < 0.001$), this finding was no longer significant after excluding women's health clinics. Additional on-treatment analysis showed significant increases in mammography ($p = 0.019$) and influenza vaccination ($p = 0.015$) for intervention arm patients who opened an eJournal compared to control arm patients, but no differences for any measure among patients who did not open an eJournal. CONCLUSIONS: Providing patients with HM reminders via a PHR may be effective in improving some elements of preventive care.

Best Practices – Annotated Bibliography

Berry, J. G., Goldmann, D. A., Mandl, K. D., Putney, H., Helm, D., O'Brien, J., . . . Weinick, R. M. (2011). Health information management and perceptions of the quality of care for children with tracheotomy: A qualitative study. *BMC Health Services Research, 11*, 117. doi:10.1186/1472-6963-11-117

BACKGROUND: Children with tracheotomy receive health care from an array of providers within various hospital and community health system sectors. Previous studies have highlighted substandard health information exchange between families and these sectors. The aim of this study was to investigate the perceptions and experiences of parents and providers with regard to health information management, care plan development and coordination for children with tracheotomy, and strategies to improve health information management for these children. **METHODS:** Individual and group interviews were performed with eight parents and fifteen healthcare (primary and specialty care, nursing, therapist, equipment) providers of children with tracheotomy. The primary tracheotomy-associated diagnoses for the children were neuromuscular impairment (n = 3), airway anomaly (n = 2) and chronic lung disease (n = 3). Two independent reviewers conducted deep reading and line-by-line coding of all transcribed interviews to discover themes associated with the objectives. **RESULTS:** Children with tracheotomy in this study had healthcare providers with poorly defined roles and responsibilities who did not actively communicate with one another. Providers were often unsure where to find documentation relating to a child's tracheotomy equipment settings and home nursing orders, and perceived that these

situations contributed to medical errors and delayed equipment needs. Parents created a home record that was shared with multiple providers to track the care that their children received but many considered this a burden better suited to providers. Providers benefited from the parent records, but questioned their accuracy regarding critical tracheotomy care plan information such as ventilator settings. Parents and providers endorsed potential improvement in this environment such as a comprehensive internet-based health record that could be shared among parents and providers, and between various clinical sites. CONCLUSIONS: Participants described disorganized tracheotomy care and health information mismanagement that could help guide future investigations into the impact of improved health information systems for children with tracheotomy. Strategies with the potential to improve tracheotomy care delivery could include defined roles and responsibilities for tracheotomy providers, and improved organization and parent support for maintenance of home-based tracheotomy records with web-based software applications, personal health record platforms and health record data authentication techniques.

Buyers Health Care Action Group. (2011). *Health care purchaser declaration*. Retrieved April 27, 2012, from <http://bhcag.com/wp-content/uploads/2011/09/HealthCarePurchaserDeclaration.pdf>

Declaration by BHCAG inviting and encouraging all health information “data holders,” - health plans, payers of medical, dental and pharmacy benefits, health care providers, pharmacies, home care device developers, health clubs, and others - to join us in increasing the efficiency, cost effectiveness and value of personal health information

management by supporting the use of a universal, secure health information repository and management site for all Minnesotans.

California Healthcare Foundation. (2007). *Best Practices for Employers Offering Personal Health Records (PHRs)*. Retrieved April 27, 2012, from <http://www.chcf.org/publications/2007/12/best-practices-for-employers-offering-personal-health-records-phrs>

While a number of companies already offer PHRs, consumer concerns about privacy safeguards and regulatory uncertainty persist. To address these issues directly, the Health Privacy Project, together with the California HealthCare Foundation and IBM, convened an Employers' Working Group on PHRs. Through a collaborative process, they developed *Best Practices for Employers Offering Personal Health Records*.

Curtis, J., Cheng, S., Rose, K., & Tsai, O. (2011). Promoting adoption, usability, and research for personal health records in Canada: the MyChart experience. *Healthcare Management Forum / Canadian College of Health Service Executives = Forum Gestion Des Soins De Sante / College Canadien Des Directeurs De Services De Sante*, 24(3), 149-154.

Sunnybrook's MyChart Personal Health Record (PHR) represents a direct extension of the hospital's electronic health record and an innovative form of healthcare record that promises to change the way patients and providers access and manage the information required to participate in their care. Early attempts at the development of PHR features have evolved into a set of emergent best practices that should directly inform the ongoing development of the MyChart platform and should be complemented with a

research agenda that supports evidence-based analysis and design considerations affecting clinical efficacy, administrative efficiency, and value generation for all PHR stakeholders.

Dolan, P. L. (2008). Privacy framework for personal health records developed. *American Medical News*, 2008(Jul 14), 2012. Retrieved from <http://www.ama-assn.org/amednews/2008/07/14/bisc0714.htm>

A PHR framework was developed by the Markle Foundation-operated Connecting for Health, a public-private collaboration that included several groups, including the American Medical Association. The framework was developed over the course of 18 months and includes 14 specific technology and policy approaches for vendors and for consumers.

Halamka, J. D., Mandl, K. D., & Tang, P. C. (2008). Early experiences with personal health records. *Journal of the American Medical Informatics Association*, 15(1), 1-7.
doi:10.1197/jamia.M2562

Over the past year, several payers, employers, and commercial vendors have announced personal health record projects. Few of these are widely deployed and few are fully integrated into ambulatory or hospital-based electronic record systems. The earliest adopters of personal health records have many lessons learned that can inform these new initiatives. We present three case studies--MyChart at Palo Alto Medical Foundation, PatientSite at Beth Israel Deaconess Medical Center, and Indivo at Children's Hospital Boston. We describe our implementation challenges from 1999 to 2007 and postulate the evolving challenges we will face over the next five years.

Markle Foundation. (2012). *Markle Common Framework: Sharing and protecting information*. Retrieved April 27, 2012, from <http://www.markle.org/health/markle-common-framework>

The Markle Connecting for Health public-private collaboration develops foundational practices for sharing personal health information in a way that preserves privacy and security. These policy and technology practices are embodied in the Markle Common Framework and endorsed by a wide range of experts and organizations. Three areas of the framework are detailed on this website: Private and Secure Information Exchange, Networked Personal Health Information, and An exploration of informed decision making for health in the 21st century.

National Center on Vital and Health Statistics. (2006). *Personal health records and personal health record systems*. Washington D.C.: U.S. Department of Health and Human Services. Retrieved from <http://www.ncvhs.hhs.gov/0602nhiirpt.pdf>

President Bush and Secretary Leavitt have put forward a vision that, in the Secretary's words, "would create a personal health record that patients, doctors and other health care providers could securely access through the Internet no matter where a patient is seeking medical care." The National Health Information Infrastructure Workgroup of the National Committee on Vital and Health Statistics (NCVHS) held six hearings on personal health records (PHRs) and PHR systems in 2002-2005. On the basis of those hearings, the Workgroup developed a letter report with twenty recommendations that it sent to the Secretary in September 2005. Citing the role PHR systems could play in improving health and healthcare and furthering the broad health information

technology agenda, the letter report urges the Secretary to exercise leadership and give priority to developing PHRs and PHR systems, consistent with the Committee's recommendations. The present report is a slightly expanded version of the letter report sent to the Secretary. Although substantively unchanged, it adds clarifying information for a broader audience.

Reti, S. R., Feldman, H. J., Ross, S. E., & Safran, C. (2010). Improving personal health records for patient-centered care. *Journal of the American Medical Informatics Association*, 17(2), 192-195. doi:10.1136/jamia.2009.000927

OBJECTIVE: To assess the patient-centeredness of personal health records (PHR) and offer recommendations for best practice guidelines. **DESIGN:** Semi-structured interviews were conducted in seven large early PHR adopter organizations in 2007. Organizations were purposively selected to represent a variety of US settings, including medium and large hospitals, ambulatory care facilities, insurers and health plans, government departments, and commercial sectors. **MEASUREMENTS:** 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; (8) coordination of care. Within this framework we used evidence for patient preferences (where it exists) to compare existing PHR policies, and propose a best practice model. **RESULTS:** 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. CONCLUSION: Findings suggest patient-centeredness for personal health records can be improved, and recommendations are made for best practice guidelines.

Roberts, J. (2009). Personal electronic health records: from biomedical research to people's health. *Informatics in Primary Care*, 17(4), 255-260.

Access to web technologies and the increased bandwidth and capacity of these systems has facilitated the development of personal electronic health records (PEHRs). This conference reports the key messages from the Friends of the National Library of Medicine (FNLM) meeting on PEHRs 'From Biomedical Research to People's Health' in May 2009. The conference provided a comprehensive overview of issues and best practice for PEHR. The key messages of the conference were: PEHR have the potential to ensure equity, continuity and healthcare quality. Electronic records may allow individuals to contribute to disease surveillance, public health and research in ways that were not previously possible. We need to prepare carefully for a 'brave new world' in which a small number of commercial organisations may become trusted custodians of the planet's medical information. Ethical dilemmas are already emerging from the use of PEHRs - largely stemming from our experiences within the UK. This report links the findings of this conference with key UK and European innovations. Informaticians, in conjunction with clinicians and solution providers, should both prepare for the realities of PEHR and more formally articulate their potential benefits and risks.

Ross, S. E., Johnson, K. B., Siek, K. A., Gordon, J. S., Khan, D. U., & Haverhals, L. M. (2011). Two complementary personal medication management applications developed on a common platform: Case report. *Journal of Medical Internet Research*, 13(3), e45. doi:10.2196/jmir.1815

BACKGROUND: Adverse drug events are a major safety issue in ambulatory care.

Improving medication self-management could reduce these adverse events.

Researchers have developed medication applications for tethered personal health records (PHRs), but little has been reported about medication applications for

interoperable PHRs. **OBJECTIVE:** Our objective was to develop two complementary personal health applications on a common PHR platform: one to assist children with complex health needs (MyMediHealth), and one to assist older adults in care

transitions (Colorado Care Tablet). **METHODS:** The applications were developed using a user-centered design approach. The two applications shared a common PHR

platform based on a service-oriented architecture. MyMediHealth employed Web and mobile phone user interfaces. Colorado Care Tablet employed a Web interface

customized for a tablet PC. **RESULTS:** We created complementary medication

management applications tailored to the needs of distinctly different user groups using common components. Challenges were addressed in multiple areas, including how to

encode medication identities, how to incorporate knowledge bases for medication images and consumer health information, how to include supplementary dosing

information, how to simplify user interfaces for older adults, and how to support

mobile devices for children. **CONCLUSIONS:** These prototypes demonstrate the utility

of abstracting PHR data and services (the PHR platform) from applications that can be

tailored to meet the needs of diverse patients. Based on the challenges we faced, we provide recommendations on the structure of publicly available knowledge resources and the use of mobile messaging systems for PHR applications.

Rubin, R. R., Borgman, S. K., & Sulik, B. T. (2011). Crossing the technology divide: Practical strategies for transitioning patients from multiple daily insulin injections to sensor-augmented pump therapy. *The Diabetes Educator, 37 Suppl 1*, 5S-18S.

doi:10.1177/01457217110391107

PURPOSE: To describe the benefits of continuous glucose monitoring (CGM) and continuous subcutaneous insulin infusion (CSII) systems compared with self-monitoring of blood glucose (SMBG) and multiple daily injection (MDI) therapy; to assess the benefits of sensor-augmented pump therapy (SAPT) in patients with type 1 diabetes; and to present an evidence-based practical protocol for introducing SAPT in patients with no prior pump or CGM experience. **CONCLUSION:** Continuous glucose monitoring and CSII have advantages over SMBG and MDI, respectively, in terms of A1C and hypoglycemia reduction. The Sensor-Augmented Pump Therapy for A1C Reduction (STAR) 3 trial demonstrated that initiating both CGM and CSII in selected adult and pediatric patients with type 1 diabetes unable to meet glycemic goals with intensive insulin injection therapy significantly improved glucose control. In all subjects using SAPT, A1C levels fell rapidly from baseline to 3 months and remained significantly lower than among subjects in the SMBG+MDI group for 1 year. A distinguishing feature of the STAR 3 study was its stepwise protocol for systematizing education and self-management support using Web-based training modules and therapy management software. The demonstrated strengths of this education protocol

recommend it as a model for implementing SAPT in the broader population of patients with type 1 diabetes who have not achieved their glycemic goals with optimized MDI therapy.

Segall, N., Saville, J. G., L'Engle, P., Carlson, B., Wright, M. C., Schulman, K., & Tcheng, J. E. (2011). Usability evaluation of a personal health record. *AMIA Annual Symposium Proceedings, 2011*, 1233-1242.

The electronic personal health record (PHR) has been championed as a mediator of patient-centered care, yet its usability and utility to patients, key predictors of success, have received little attention. Human-centered design (HCD) offers validated methods for studying systems effects on users and their cognitive tasks. In HCD, user-centered activities allow potential users to shape the design of the end product and enhance its usability. We sought to evaluate the usability and functionality of HealthView, the PHR of the Duke University Health System, using HCD methods. Study participants were asked to think aloud as they carried out tasks in HealthView. They then completed surveys and interviews eliciting their reactions to the web portal. Findings were analyzed to generate redesign recommendations, which will be incorporated in a future release of HealthView.

Tague, R., Maeder, A. J., & Nguyen, Q. V. (2010). Time-based interactive visualisation of vital signs. *Studies in Health Technology and Informatics*, 161, 169-178.

Physiological vital signs are important factors for clinical processes like tele-assessment, tele-monitoring and tele-treatment of patients. Records of patient vital signs over time are complex to understand without proper visualisation and data

analysis aids. We present a model for interactively visualising vital signs in patient data histories, as used for remote chronic disease management. Our model allows simultaneous access to all vital signs records for the patient along a time-based axis. Clinicians and other health carers can then apply generalisation and refinement 'lenses' in a multi-layering visualisation mechanism to examine records further over single or multiple time sessions. The model also includes rule-based decisions for issuing notifications, when expected limits are exceeded.

Tuil, W. S., van Selm, M., Verhaak, C. M., de Vries Robbe, P. F., & Kremer, J. A. (2009).

Dynamics of Internet usage during the stages of in vitro fertilization. *Fertility and Sterility*, 91(3), 953-956. doi:10.1016/j.fertnstert.2007.12.059

Hospitals and clinics develop Internet strategies to emancipate and empower their patient population. At Radboud University Nijmegen Medical Centre, we developed an Internet-based personal health record that provides patients with general and personal information about their treatment and that provides facilities for communication with fellow patients and with physicians. Because not much is known about information and communication needs of IVF and ICSI patients in relation to their treatment, we observed the intensity of use of this personal health record during the various stages of IVF treatment. We measured the numbers of page views and the number of contributions to the chat room. Data regarding Website use and treatment schedules were available for 51 couples. These couples generated 25,420 page views and posted 11,403 utterances. Two-way analysis of variance showed that significant individual changes occurred in the intensity of use during the different stages of the treatment. During the stages in which there is no contact between the patient and the

clinic, patients make use of the Website's communication functions. This reflects the patients' need for continued communication and support during the last stages of treatment, a service that IVF clinics traditionally cannot or do not provide.

Van Deursen, T., Koster, P., & Petkovic, M. (2008). Reliable personal health records. *Studies in Health Technology and Informatics*, 136, 484-489.

A number of applications based on personal health records (PHRs) are emerging in the field of health care and wellness. PHRs empower patients by giving them control over their health data. Health data for PHRs can be supplied by patients, wellness providers and health care providers. Health care providers may use the PHRs to provide medical care. Unfortunately, the quality of the health data in PHRs cannot be guaranteed in all cases. For example, consider cases where non-professionals such as patients and wellness providers supply data. To address this problem, we present in this paper a system that provides health care professionals with an indication of the quality of health data in a PHR. This indication is based on the reputation of the supplier and on metadata provided by measurement devices. The proposed reputation system mimics the way in which trust in health data and their suppliers is built in the real world. The system introduces minimal overhead for health care providers and patients.

Wicks, P., Massagli, M., Frost, J., Brownstein, C., Okun, S., Vaughan, T., . . . Heywood, J. (2010). Sharing health data for better outcomes on PatientsLikeMe. *Journal of Medical Internet Research*, 12(2), e19. doi:10.2196/jmir.1549

BACKGROUND: PatientsLikeMe is an online quantitative personal research platform for patients with life-changing illnesses to share their experience using patient-

reported outcomes, find other patients like them matched on demographic and clinical characteristics, and learn from the aggregated data reports of others to improve their outcomes. The goal of the website is to help patients answer the question: "Given my status, what is the best outcome I can hope to achieve, and how do I get there?"

OBJECTIVE: Using a cross-sectional online survey, we sought to describe the potential benefits of PatientsLikeMe in terms of treatment decisions, symptom management, clinical management, and outcomes. **METHODS:** Almost 7,000 members from six PatientsLikeMe communities (amyotrophic lateral sclerosis [ALS], Multiple Sclerosis [MS], Parkinson's Disease, human immunodeficiency virus [HIV], fibromyalgia, and mood disorders) were sent a survey invitation using an internal survey tool (PatientsLikeMe Lens). **RESULTS:** Complete responses were received from 1323 participants (19% of invited members). Between-group demographics varied according to disease community. Users perceived the greatest benefit in learning about a symptom they had experienced; 72% (952 of 1323) rated the site "moderately" or "very helpful." Patients also found the site helpful for understanding the side effects of their treatments (n = 757, 57%). Nearly half of patients (n = 559, 42%) agreed that the site had helped them find another patient who had helped them understand what it was like to take a specific treatment for their condition. More patients found the site helpful with decisions to start a medication (n = 496, 37%) than to change a medication (n = 359, 27%), change a dosage (n = 336, 25%), or stop a medication (n = 290, 22%). Almost all participants (n = 1,249, 94%) were diagnosed when they joined the site. Most (n = 824, 62%) experienced no change in their confidence in that diagnosis or had an increased level of confidence (n = 456, 34%). Use of the site was

associated with increasing levels of comfort in sharing personal health information among those who had initially been uncomfortable. Overall, 12% of patients (n = 151 of 1320) changed their physician as a result of using the site; this figure was doubled in patients with fibromyalgia (21%, n = 33 of 150). Patients reported community-specific benefits: 41% of HIV patients (n = 72 of 177) agreed they had reduced risky behaviors and 22% of mood disorders patients (n = 31 of 141) agreed they needed less inpatient care as a result of using the site. Analysis of the Web access logs showed that participants who used more features of the site (eg, posted in the online forum) perceived greater benefit. CONCLUSIONS: We have established that members of the community reported a range of benefits, and that these may be related to the extent of site use. Third party validation and longitudinal evaluation is an important next step in continuing to evaluate the potential of online data-sharing platforms.

Zeng-Treitler, Q., Kim, H., Goryachev, S., Keselman, A., Slaughter, L., & Smith, C. A. (2007).

Text characteristics of clinical reports and their implications for the readability of personal health records. *Studies in Health Technology and Informatics*, 129(Pt 2), 1117-1121.

Through personal health record applications (PHR), consumers are gaining access to their electronic health records (EHR). A new challenge is to make the content of these records comprehensible to consumers. To address this challenge, we analyzed the text unit length, syntactic and semantic characteristics of three sets of health texts: clinical reports from EHR, known difficult materials and easy-to-read materials. Our findings suggest that EHR texts are more different from easy texts and more similar to difficult texts in terms of syntactic and semantic characteristics, and EHR texts are more similar

to easy texts and different from difficult texts in regard to text unit length features. Since commonly used readability formulas focus more on text unit length characteristics, this study points to the need to tackle syntactic and semantic issues in the effort to measure and improve PHR readability.

Costs: Annotated Bibliography

Allison, M. (2009). Can web 2.0 reboot clinical trials? *Nature Biotechnology*, 27(10), 895-902. doi:10.1038/nbt1009-895

Dozens of companies are trying to leverage social networking and other software tools to accelerate trials and reduce their cost.

Detmer, D., Bloomrosen, M., Raymond, B., & Tang, P. (2008). Integrated personal health records: Transformative tools for consumer-centric care. *BMC Medical Informatics and Decision Making*, 8, 45. doi:10.1186/1472-6947-8-45

BACKGROUND: Integrated personal health records (PHRs) offer significant potential to stimulate transformational changes in health care delivery and self-care by patients. In 2006, an invitational roundtable sponsored by Kaiser Permanente Institute, the American Medical Informatics Association, and the Agency for Healthcare Research and Quality was held to identify the transformative potential of PHRs, as well as barriers to realizing this potential and a framework for action to move them closer to the health care mainstream. This paper highlights and builds on the insights shared during the roundtable. DISCUSSION: While there is a spectrum of dominant PHR models, (standalone, tethered, integrated), the authors state that only the integrated model has true transformative potential to strengthen consumers' ability to manage their own health care. Integrated PHRs improve the quality, completeness, depth, and accessibility of health information provided by patients; enable facile communication between patients and providers; provide access to health knowledge for patients; ensure portability of medical records and other personal health information; and

incorporate auto-population of content. Numerous factors impede widespread adoption of integrated PHRs: obstacles in the health care system/culture; issues of consumer confidence and trust; lack of technical standards for interoperability; lack of HIT infrastructure; the digital divide; uncertain value realization/ROI; and uncertain market demand. Recent efforts have led to progress on standards for integrated PHRs, and government agencies and private companies are offering different models to consumers, but substantial obstacles remain to be addressed. Immediate steps to advance integrated PHRs should include sharing existing knowledge and expanding knowledge about them, building on existing efforts, and continuing dialogue among public and private sector stakeholders. SUMMARY: Integrated PHRs promote active, ongoing patient collaboration in care delivery and decision making. With some exceptions, however, the integrated PHR model is still a theoretical framework for consumer-centric health care. The authors pose questions that need to be answered so that the field can move forward to realize the potential of integrated PHRs. How can integrated PHRs be moved from concept to practical application? Would a coordinating body expedite this progress? How can existing initiatives and policy levers serve as catalysts to advance integrated PHRs?

Johnston, D., Kaelber, D., Pan, E. C., Bu, D., Shah, S., Hook, J. M., & Middleton, B. (2007). A framework and approach for assessing the value of personal health records (PHRs). *AMIA ...Annual Symposium Proceedings, 2007*, 374-378.

Personal Health Records (PHRs) are a rapidly expanding area of medical informatics due to the belief that they may improve health care delivery and control costs of care.

The PHRs in use or in development today support a myriad of different functions, and

consequently offer different value propositions. A comprehensive value analysis of PHRs has never been conducted; such analysis is needed to identify those PHR functions that yield the greatest value to PHR stakeholders. Here we present a framework that could serve as a foundation for determining the value of PHR functions and thereby help optimize PHR development. While the value framework is specific to the domain of PHRs, the authors have successfully applied the associated evaluation methodology in assessing other health care information technologies.

Kaelber, D., & Pan, E. C. (2008). The value of personal health record (PHR) systems. [] *AMIA Annual Symposium Proceedings, 2008*, 343-347.

Personal health records (PHRs) are a rapidly growing area of health information technology despite a lack of significant value-based assessment. Here we present an assessment of the potential value of PHR systems, looking at both costs and benefits. We examine provider-tethered, payer-tethered, and third-party PHRs, as well as idealized interoperable PHRs. An analytical model was developed that considered eight PHR application and infrastructure functions. Our analysis projects the initial and annual costs and annual benefits of PHRs to the entire US over the next 10 years. This PHR analysis shows that all forms of PHRs have initial net negative value. However, at the end of 10 years, steady state annual net value ranging from \$13 billion to -\$29 billion. Interoperable PHRs provide the most value, followed by third-party PHRs and payer-tethered PHRs also showing positive net value. Provider-tethered PHRs constantly demonstrating negative net value.

Kaelber, D. C., Jha, A. K., Johnston, D., Middleton, B., & Bates, D. W. (2008). A research agenda for personal health records (PHRs). [

] *Journal of the American Medical Informatics Association : JAMIA*, 15(6), 729-736.

doi:10.1197/jamia.M2547

Patients, policymakers, providers, payers, employers, and others have increasing interest in using personal health records (PHRs) to improve healthcare costs, quality, and efficiency. While organizations now invest millions of dollars in PHRs, the best PHR architectures, value propositions, and descriptions are not universally agreed upon. Despite widespread interest and activity, little PHR research has been done to date, and targeted research investment in PHRs appears inadequate. The authors reviewed the existing PHR specific literature (100 articles) and divided the articles into seven categories, of which four in particular--evaluation of PHR functions, adoption and attitudes of healthcare providers and patients towards PHRs, PHR related privacy and security, and PHR architecture--present important research opportunities. We also briefly discuss other research related to PHRs, PHR research funding sources, and PHR business models. We believe that additional PHR research can increase the likelihood that future PHR system deployments will beneficially impact healthcare costs, quality, and efficiency.

Kahn, J. S., Aulakh, V., & Bosworth, A. (2009). What it takes: Characteristics of the ideal personal health record. *Health Affairs (Project Hope)*, 28(2), 369-376.

doi:10.1377/hlthaff.28.2.369

There is a gap between today's personal health records (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.

McKinney, M. (2009). CMS and the Defense Department pilot projects could jump-start PHR use. [

] *H&HN: Hospitals & Health Networks*, 83(3), 9-9.

This article reports that very few Americans actually use personal health records (PHR) in spite of high interest, according to Manhattan Research. It is estimated that 70 million consumers are interested in having a PHR but only seven million actively use one. Experts are hoping that large-scale projects by the Centers for Medicare & Medicaid Services (CMS) and the Department of Defense will mainstream PHRs and boost adoption. A CMS pilot project launched in Arizona and Utah aims to test whether PHRs enhance patient outcomes and reduce the cost of care.

Shah, S., Kaelber, D. C., Vincent, A., Pan, E. C., Johnston, D., & Middleton, B. (2008). A cost model for personal health records (PHRs). *AMIA Annual Symposium Proceedings, 2008*, 657-661.

Personal health records (PHRs) are a rapidly expanding area in medical informatics due to the belief that they may improve healthcare delivery and control costs of care.

To truly understand the full potential value of a technology, a cost analysis is

critical. However, little evidence exists on the value potential of PHRs, and a cost model for PHRs does not currently exist in the literature. This paper presents a sample cost model for PHR systems, which include PHR infrastructure and applications. We used this model to examine the costs of provider-tethered, payer-tethered, third-party, and interoperable PHRs. Our model projects that on a per-person basis, third-party PHRs will be the most expensive followed by inter operable PHRs, and then provider-tethered PHRs and payer-tethered PHRs are the least expensive. Data interfaces are a major cost driver, thus these findings underscore the need for standards development and use in the implementation of PHR systems.

Singh, K., & Kvedar, J. C. (2009). Innovations in connected health. *Studies in Health Technology and Informatics*, 149, 111-129.

Technological advancements in recent decades have made the concept of Connected Health feasible. These innovations include hardware innovations (such as wearable medical technology), and software (such as electronic personal health record systems e.g., Google Health and Microsoft HealthVault). Technology innovations must be accompanied by process innovations to truly add value. In health care that includes clinical process innovations and business process innovations. This chapter outlines how the healthcare system is being affected by innovations in connected health. It provides examples that illustrate the various categories of innovation and their impact. Now more than ever, health care reform is required in the U.S. The systems outlined in this chapter will allow care that is of high quality, while extending providers across more patients (i.e. increasing access) at a lower overall cost (improved efficiency).

Steward, D. A., Hofler, R. A., Thaldorf, C., & Milov, D. E. (2010). A method for understanding some consequences of bringing patient-generated data into health care delivery. *Medical Decision Making : An International Journal of the Society for Medical Decision Making*, 30(4), E1-E13. doi:10.1177/0272989X10371829

OBJECTIVE: The consequences of personal health record (PHR) phenomena on the health care system are poorly understood. This research measures one aspect of the phenomena--the time-cost impact of patient-generated data (PGD) using discrete event model (DEM) simulation. BACKGROUND/SIGNIFICANCE: Little has been written about the temporal and cognitive burden associated with new workflows that include PGD. This pilot study reports the results for time-cost and resource utilization of a "typical" ambulatory clinic under varying conditions of PGD burden. METHODS: PGD effects are modeled with DEM simulation reflecting the sequential relationships, temporal coupling, and impact assumptions within a virtual clinic. Three simulation scenarios of ever-increasing PGD impact are compared to a baseline case of no PGD use. RESULTS: Introduction of PGD resulted in expected increases in cost and resource utilization along with a few key exceptions and unanticipated consequences. Direct and indirect impacts were observed with notable nonlinear, nonadditive, disproportionate, heterogeneous aspects and interactions among consequent labor cost, visit length, workday length, and resource utilization. The middle-impact simulations showed a 29% increase in daily labor costs and 28% shrinkage of the margin between revenues and labor costs. Lengths of both workday and patient visit were extended and less predictable with PGD use. Utilization rates of most staff positions rose. Nurse utilization rates showed greatest increases. Physicians'

utilization rates paradoxically stayed relatively unchanged. CONCLUSION: This analysis contributes to an understanding of the effects of PGD on time and cognitive burdens of physicians, staff, and physical resources. It illustrates the usefulness of DEM simulation for the purpose. Avoidable consequences are exposed quantifiably for both the patient and the clinic. More realistic ways to respond to PGD impact are needed.

Tang, P. C., Ash, J. S., Bates, D. W., Overhage, J. M., & Sands, D. Z. (2006). Personal health records: Definitions, benefits, and strategies for overcoming barriers to adoption. *Journal of the American Medical Informatics Association : JAMIA*, 13(2), 121-126.
doi:10.1197/jamia.M2025

Recently there has been a remarkable upsurge in activity surrounding the adoption of personal health record (PHR) systems for patients and consumers. The biomedical literature does not yet adequately describe the potential capabilities and utility of PHR systems. In addition, the lack of a proven business case for widespread deployment hinders PHR adoption. In a 2005 working symposium, the American Medical Informatics Association's College of Medical Informatics discussed the issues surrounding personal health record systems and developed recommendations for PHR-promoting activities. Personal health record systems are more than just static repositories for patient data; they combine data, knowledge, and software tools, which help patients to become active participants in their own care. When PHRs are integrated with electronic health record systems, they provide greater benefits than would stand-alone systems for consumers. This paper summarizes the College Symposium discussions on PHR systems and provides definitions, system

characteristics, technical architectures, benefits, barriers to adoption, and strategies for increasing adoption.

Tang, P. C., Black, W., & Young, C. Y. (2006). Proposed criteria for reimbursing eVisits:

Content analysis of secure patient messages in a personal health record system. *AMIA Annual Symposium Proceedings, 2006*, 764-768.

The Institute of Medicine called for healthcare organizations to provide care whenever needed, using the Internet as appropriate. Few organizations currently offer clinical electronic messaging services for their patients. Many believe that broader adoption of online services will not occur without a change in reimbursement policies. We propose modified Evaluation and Management (eVisit E&M) criteria derived from the current office-based E&M codes as a means of qualifying whether an online encounter should be reimbursed. Physician reviewers applied the proposed eVisit criteria to 120 randomly selected electronic messages sent by 112 patients to 69 physicians through a personal health record system. Twenty-two percent of clinical messages to physicians contained sufficient patient-history data and medical decision-making components to warrant reimbursement according to our eVisit criteria. Among a subset of patients with multiple chronic diseases, this would have generated an estimated 1.2 eVisits per patient annually. Across a broader patient population, we estimate that 0.7 eVisit encounters would be generated annually per patient. Sixty-five percent (65%) of patients felt that electronic communication with their physicians saved one or more office visits per year. Reimbursing for qualified eVisits may encourage broader use of electronic communication to improve access to care and reduce overall healthcare costs.

Wynia, M., & Dunn, K. (2010). Dreams and nightmares: Practical and ethical issues for patients and physicians using personal health records. *Journal of Law, Medicine & Ethics*, 38(1), 64-73. doi:10.1111/j.1748-720X.2010.00467.x

Electronic health records for patients, personal health records (PHRs), have become increasingly popular among policy makers and purchasers, but uptake among patients and physicians has been relatively slow. PHRs have varying uses that might make them more or less appealing to different stakeholders. The three core uses for PHRs - promoting communication, data use, and patient responsibility - each raises a set of potential practical and financial dilemmas. But some ethical concerns are also at play, some of which are rarely recognized as values-based barriers to the use of PHRs. Recognizing these ethical issues, and addressing them explicitly in PHR design and policy making, would help PHRs to achieve their promise.

Definitions and Functions: Annotated Bibliography

Ackerman, M. J. (2007). The personal health record. *Journal of Medical Practice Management, 23*(2), 84-85.

Brief editorial about the importance of a PHR. Identifies that for information to be shared effectively, all providers must have a standardized, network-accessible health record, and encourage patients to use integrated PHRs

AHIMA e-HIM Personal Health Record Work Group. (2005). Practice brief. The role of the personal health record in the EHR. *Journal of AHIMA, 76*(7), 64A-64D.

This article is a practice brief linking the work of the Markle Foundation to the AHIMA effort to encourage the use of PHRs. It provide definitions, features, and functions of a PHR.

AHIMA Personal Health Record Practice Council, Burrington-Brown, J., Claybrook, D., Fox, L., Gould, K., Hall, L., . . . Sweet, D. (2006). Helping consumers select PHRs. *Journal of AHIMA, 77*(10), 50-4, 56; quiz 59-60.

The article includes information about what consumers should ask when selecting a PHR. It also includes attributes of emerging PHRs.

Ahmadi, M., Jeddi, F. R., Gohari, M. R., & Sadoughi, F. (2012). A review of the personal health records in selected countries and Iran. *Journal of Medical Systems, 36*(2), 371-82.

doi:10.1007/s10916-010-9482-3

Personal Health Record (PHR) enables patients to access their health information and improves care quality by supporting self-care. The purpose of this study is to provide a comparative analysis of the concept of PHRs in selected countries and Iran in order to

investigate the gaps between Iran and more advanced countries in terms of PHRs. The study was carried out in 2008-2009 using a descriptive-comparative method in Australia, the United States, England and Iran. Data was gathered from articles, books, journals and reputed websites in English and Persian published between 1995 and September 2009. After collecting the data, both advantages and disadvantages of each of concepts were analyzed. In the three countries considered in the present study the concepts of PHR, extracted from the literature, are that; a) patient/person be recognized as the owner of PHR; b) information be disclosed only to those authorized by the patient; c) and that PHR is created upon request and consent of the individual involved. Before PHRs can be profitably used in the health administration of a (developing) country, the necessary knowledge, infrastructures, and rules need to be developed.

Allaert, F. A., & Quantin, C. (2010). Patients' empowerment of their personal health record requires strong traceability to guarantee patients health care security. *Studies in Health Technology and Informatics*, 155, 43-47.

Giving patients power over their personal health record is an unavoidable evolution in all industrialized countries which will reflect their active participation in the management of their own health. This would lead to patients sharing management with health professionals, which would need traceability of the data provider to maintain trust and transparency. The systematic use of electronic signatures by medical practitioners will be essential to provide sufficient guarantees and to clearly determine who has added what in the PEHR.

American Health Information Management Association, & American Medical Informatics Association. (2008). The value of personal health records. A joint position statement for consumers of health care. *Studies in Health Technology and Informatics*, 137, 402-405.

“The American Health Information Management Association (AHIMA) and the American Medical Informatics Association (AMIA) advocate empowering individuals to manage their healthcare through the use of a personal health record (PHR). The PHR is a tool for collecting, tracking and sharing important, up-to-date, information about an individual’s health or the health of someone in their care. Using a PHR will help people make better health decisions and improves quality of care by allowing them to access and use information needed to communicate effectively with others about their healthcare” (AHIMA).

The AHIMA and AMIA encourage consumers to begin tracking their health information in whatever format works best for the consumer, even if the method of tracking is paper. However, electronic media is recommended for a timely, accurate, and secure exchange of information.

“The American Health Information Management Association (AHIMA) and the American Medical Informatics Association (AMIA) advocate empowering individuals to manage their healthcare through the use of a personal health record (PHR). The PHR is a tool for collecting, tracking and sharing important, up-to-date, information about an individual’s health or the health of someone in their care. Using a PHR will help people make better health decisions and improves quality of care by allowing them to access

and use information needed to communicate effectively with others about their healthcare” (AHIMA).

Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbin, K. A., & Straus, S. E. (2011). Personal health records: A scoping review. *Journal of the American Medical Informatics Association, 18*(4), 515-522. doi:10.1136/amiajnl-2011-000105

Electronic personal health record systems (PHRs) support patient centered healthcare by making medical records and other relevant information accessible to patients, thus assisting patients in health self-management. We reviewed the literature on PHRs including design, functionality, implementation, applications, outcomes, and benefits. We found that, because primary care physicians play a key role in patient health, PHRs are likely to be linked to physician electronic medical record systems, so PHR adoption is dependent on growth in electronic medical record 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.

Ball, M. J., & Gold, J. (2006). Banking on health: Personal records and information exchange. *Journal of Healthcare Information Management, 20*(2), 71-83.

Consumer demand for personal health records (PHRs) and the capabilities provided by regional health information organizations (RHIOs) will change healthcare, just as

automatic teller machines have changed banking. The PHR is predicated on the existence of electronic medical records (EMRs) and electronic health records (EHRs). Patient and consumer principles guiding the development of the PHR reflect issues of access, control, privacy, and security. Working models illustrate the variations of RHIOs and PHRs possible and suggest the benefits that electronic information exchange can accrue for healthcare and healthcare consumers. Today both the private and public sectors are working to define the issues involved in efforts that are now taking place and that will transform healthcare. Consumers are ready for the type of changes that will improve healthcare quality.

Ball, M. J., Smith, C., & Bakalar, R. S. (2007). Personal health records: Empowering consumers. *Journal of Healthcare Information Management*, 21(1), 76-86.

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

Baumlin, K. M., Genes, N., Landman, A., Shapiro, J. S., Taylor, T., Janiak, B., & 2010 Academic emergency medicine consensus conference Beyond regionalization: Intergrated networks of emergency care. (2010). Electronic collaboration: Using technology to solve old problems of quality care. *Academic Emergency Medicine*, 17(12), 1312-1321. doi:10.1111/j.1553-2712.2010.00933.x; 10.1111/j.1553-2712.2010.00933.x

The participants of the Electronic Collaboration working group of the 2010 Academic Emergency Medicine consensus conference developed recommendations and research questions for improving regional quality of care through the use of electronic collaboration. A writing group devised a working draft prior to the meeting and presented this to the breakout session at the consensus conference for input and approval. The recommendations include: 1) patient health information should be available electronically across the entire health care delivery system from the 9-1-1 call to the emergency department (ED) visit through hospitalization and outpatient care, 2) relevant patient health information should be shared electronically across the entire health care delivery system, 3) Web-based collaborative technologies should be employed to facilitate patient transfer and timely access to specialists, 4) personal health record adoption should be considered as a way to improve patient health, and 5) any comprehensive reform of regionalization in emergency care must include telemedicine. The workgroup emphasized the need for funding increases so that research in this new and exciting area can expand.

Benhamou, P. Y. (2011). Improving diabetes management with electronic health records and patients' health records. *Diabetes & Metabolism*, 37(Suppl 4), S53-6.

doi:10.1016/S1262-3636(11)70966-1

The lack of patient engagement and clinical inertia both contribute to suboptimal diabetes care. However, both obstacles are amenable to informatics- and Internet-based interventions. The use of electronic medical records (EMRs) is now established as being useful for improving diabetes care. Intelligent records that integrate computerized decision-support systems are now able to recommend care protocols tailored to risk levels. Web-based personal health record (PHR) systems, shared with healthcare providers, could also provide added value by promoting self-management of the behaviours related to diabetes. These Web-based programmes include patients' access to EMRs, uploading of glucose monitoring results, a glucose diary, secure e-mail with providers, manual or automated feedback on blood glucose readings and other risk factors, an educational website, and an online diary for entering personal information on exercise, diet and medication. The integration of Web-based patients' systems into the EMR used by physicians is the next frontier. In addition, the input from "smartphones" that are able to provide real-time support to patients could contribute to the reorganization of diabetes care. Convincing data on HbA(1c) improvements with such systems are available for type 2 diabetes, but are still equivocal for type 1 diabetes. Obstacles include patients' compliance with the technology, their ergonomic design and the need to reimburse providers for their care. Designing appropriate electronic tools and tailoring them to the conditions in France merits our attention.

Burrington-Brown, J., Claybrook, D., Dolan, M., Goethals, C., Kelly, C. D., LaMoureaux, L., . . .
Personal Health Record Practice Council. (2008). Defining the personal health
information management role. *Journal of AHIMA*, 79(6), 59-63.

This paper provides definitions for PHR and then discusses the role an HIM professional might perform in order to increase PHR use in consumers. AHIMA definition from 2006.

Burrington-Brown, J., Fishel, J., Fox, L., Friedman, B., Giannangelo, K., Jacobs, E., . . . AHIMA e-HIM Personal Health Record Work Group. (2005). Defining the personal health record. AHIMA releases definition, attributes of consumer health record. *Journal of AHIMA*, 76(6), 24-25.

The article includes information about what consumers should ask when selecting a PHR. It also includes attributes of emerging PHRs.

Collins, S. A., Vawdrey, D. K., Kukafka, R., & Kuperman, G. J. (2011). Policies for patient access to clinical data via PHRs: Current state and recommendations. *Journal of the American Medical Informatics Association*, 18 Suppl 1(Suppl 1), i2-7.

doi:10.1136/amiajnl-2011-000400

OBJECTIVE: Healthcare delivery organizations are increasingly using online personal health records (PHRs) to provide patients with direct access to their clinical information; however, there may be a lack of consistency in the data made available. We aimed to understand the general use and functionality of PHRs and the organizational policies and decision-making structures for making data available to patients. **MATERIALS AND METHODS:** A cross-sectional survey was administered by telephone structured interview to 21 organizations to determine the types of data made available to patients through PHRs and the presence of explicit governance for PHR data release. Organizations were identified based on a review of the literature,

PHR experts, and snowball sampling. Organizations that did not provide patients with electronic access to their data via a PHR were excluded. RESULTS: Interviews were conducted with 17 organizations for a response rate of 81%. Half of the organizations had explicit governance in the form of a written policy that outlined the data types made available to patients. Overall, 88% of the organizations used a committee structure for the decision-making process and included senior management and information services. All organizations sought input from clinicians. Discussion There was considerable variability in the types of clinical data and the time frame for releasing these data to patients. Variability in data release policies may have implications for PHR use and adoption. CONCLUSIONS: Future policy activities, such as requirement specification for the latter stages of Meaningful Use, should be leveraged as an opportunity to encourage standardization of functionality and broad deployment of PHRs.

Conn, J. (2006). Personal and (maybe) confidential. Questions over privacy, formats and definitions remain, but personal health records are on the way. *Modern Healthcare*, 36(27), 28-31.

Brief report about CMS giving PHRs another huge boost by awarding contracts to two vendors to develop pilot programs to demonstrate how user-friendly PHRs could be generated from claims data for 42.1 million Medicare beneficiaries. A definition from AHIMA is provided about what is a PHR, and then a several events and vendors who laid the foundation for PHR development are mentioned. Privacy issues are briefly discussed as are standards for PHRs.

Edlin, M. (2006). Implementing personal health records. *AHIP Coverage*, 47(2), 14-6, 19.

This article describes efforts by health insurance plans to develop and deploy PHRs.

Friedman, D. J., & Parrish, R. G., 2nd. (2010). The population health record: concepts, definition, design, and implementation. *Journal of the American Medical Informatics Association*, 17(4), 359-366. doi:10.1136/jamia.2009.001578

In 1997, the American Medical Informatics Association proposed a US information strategy that included a population health record (PopHR). Despite subsequent progress on the conceptualization, development, and implementation of electronic health records and personal health records, minimal progress has occurred on the PopHR. Adapting International Organization for Standardization electronic health records standards, we define the PopHR as a repository of statistics, measures, and indicators regarding the state of and influences on the health of a defined population, in computer processable form, stored and transmitted securely, and accessible by multiple authorized users. The PopHR is based upon an explicit population health framework and a standardized logical information model. PopHR purpose and uses, content and content sources, functionalities, business objectives, information architecture, and system architecture are described. Barriers to implementation and enabling factors and a three-stage implementation strategy are delineated.

Gaskin, G. L., Longhurst, C. A., Slayton, R., & Das, A. K. (2011). Sociotechnical challenges of developing an interoperable personal health record: Lessons learned. *Applied Clinical Informatics*, 2(4), 406-419. doi:10.4338/ACI-2011-06-RA-0035

OBJECTIVES: To analyze sociotechnical issues involved in the process of developing an interoperable commercial Personal Health Record (PHR) in a hospital setting, and to

create guidelines for future PHR implementations. METHODS: This qualitative study utilized observational research and semi-structured interviews with 8 members of the hospital team, as gathered over a 28 week period of developing and adapting a vendor-based PHR at Lucile Packard Children's Hospital at Stanford University. A grounded theory approach was utilized to code and analyze over 100 pages of typewritten field notes and interview transcripts. This grounded analysis allowed themes to surface during the data collection process which were subsequently explored in greater detail in the observations and interviews. RESULTS: Four major themes emerged: (1) Multidisciplinary teamwork helped team members identify crucial features of the PHR; (2) Divergent goals for the PHR existed even within the hospital team; (3) Differing organizational conceptions of the end-user between the hospital and software company differentially shaped expectations for the final product; (4) Difficulties with coordination and accountability between the hospital and software company caused major delays and expenses and strained the relationship between hospital and software vendor. CONCLUSIONS: Though commercial interoperable PHRs have great potential to improve healthcare, the process of designing and developing such systems is an inherently sociotechnical process with many complex issues and barriers. This paper offers recommendations based on the lessons learned to guide future development of such PHRs.

Ho, J. (2010). Consumer health informatics. *Studies in Health Technology and Informatics*, 151, 185-194.

This chapter gives an educational overview of: * The concept of consumer health

informatics * Technologies being used to empowered consumers today * The impact of these new technologies on the health care delivery models.

Hufnagel, S. P. (2009). Interoperability. *Military Medicine*, 174(5 Suppl), 43-50.

The main themes of this panel were patient safety and interoperability, the evolution of the traditional longitudinal health record into a patient managed personal health record (PHR) and the personalization of healthcare itself. The interoperability track D of the National Forum posed the following questions: (1) "How do we achieve syntactic interoperability?"; (2) "How do we achieve semantic interoperability?"; (3) "How do we evolve with emerging standards?"; (4) "How do we integrate new medical devices?"; and (5) "How do we achieve National Health Information Network interoperability?"

Johnston, D., Kaelber, D., Pan, E. C., Bu, D., Shah, S., Hook, J. M., & Middleton, B. (2007). A framework and approach for assessing the value of personal health records (PHRs). *AMIA ...Annual Symposium Proceedings, 2007*, 374-378.

Personal Health Records (PHRs) are a rapidly expanding area of medical informatics due to the belief that they may improve health care delivery and control costs of care. The PHRs in use or in development today support a myriad of different functions, and consequently offer different value propositions. A comprehensive value analysis of PHRs has never been conducted; such analysis is needed to identify those PHR functions that yield the greatest value to PHR stakeholders. Here we present a framework that could serve as a foundation for determining the value of PHR functions and thereby help optimize PHR development. While the value framework is specific to

the domain of PHRs, the authors have successfully applied the associated evaluation methodology in assessing other health care information technologies.

Jones, D. A., Shipman, J. P., Plaut, D. A., & Selden, C. R. (2010). Characteristics of personal health records: Findings of the Medical Library Association/National Library of Medicine Joint Electronic Personal Health Record Task Force. *Journal of the Medical Library Association*, 98(3), 243-249. doi:10.3163/1536-5050.98.3.013

OBJECTIVES: The Medical Library Association (MLA)/National Library of Medicine (NLM) Joint Electronic Personal Health Record Task Force examined the current state of personal health records (PHRs). METHODS: A working definition of PHRs was formulated, and a database was built with fields for specified PHR characteristics. PHRs were identified and listed. Each task force member was assigned a portion of the list for data gathering. Findings were recorded in the database. RESULTS: Of the 117 PHRs identified, 91 were viable. Almost half were standalone products. A number used national standards for nomenclature and/or record structure. Less than half were mobile device enabled. Some were publicly available, and others were offered only to enrollees of particular health plans or employees at particular institutions. A few were targeted to special health conditions. CONCLUSIONS: The PHR field is very dynamic. While most PHR products have some common elements, their features can vary. PHRs can link their users with librarians and information resources. MLA and NLM have taken an active role in making this connection and in encouraging librarians to assume this assistance role with PHRs.

Kaelber, D. C., Jha, A. K., Johnston, D., Middleton, B., & Bates, D. W. (2008). A research agenda for personal health records (PHRs). *Journal of the American Medical Informatics Association*, 15(6), 729-736. doi:10.1197/jamia.M2547

Patients, policymakers, providers, payers, employers, and others have increasing interest in using personal health records (PHRs) to improve healthcare costs, quality, and efficiency. While organizations now invest millions of dollars in PHRs, the best PHR architectures, value propositions, and descriptions are not universally agreed upon. Despite widespread interest and activity, little PHR research has been done to date, and targeted research investment in PHRs appears inadequate. The authors reviewed the existing PHR specific literature (100 articles) and divided the articles into seven categories, of which four in particular--evaluation of PHR functions, adoption and attitudes of healthcare providers and patients towards PHRs, PHR related privacy and security, and PHR architecture--present important research opportunities. We also briefly discuss other research related to PHRs, PHR research funding sources, and PHR business models. We believe that additional PHR research can increase the likelihood that future PHR system deployments will beneficially impact healthcare costs, quality, and efficiency.

Kim, J., & Bates, D. W. (2011). Analysis of the definition and utility of personal health records using q methodology. *Journal of Medical Internet Research*, 13(4), e105. doi:10.2196/jmir.1781

BACKGROUND: Personal health records (PHRs) remain a relatively new technology and concept in practice even though they have been discussed in the literature for more than 50 years. There is no consensus on the definition of a PHR or PHR system

even within the professional societies of health information technology. OBJECTIVE: Our objective was to analyze and classify the opinions of health information professionals regarding the definitions of the PHR. METHOD: Q methodology was used to explore the concept of the PHR. A total of 50 Q-statements were selected and rated by 45 P-samples consisting of health information professionals. We analyzed the resulting data by using Q methodology-specific software and SPSS. RESULT: We selected five types of health information professionals' opinions: type I, public interest centered; type II, health information standardization centered; type III, health consumer centered; type IV, health information security centered; and type V, health consumer convenience centered. The Q-statements with the highest levels of agreement were as follows: (1) the PHR is the lifetime record of personal health information, (2) the PHR is the representation of health 2.0, and (3) security is the most important requirement of the PHR. The most disagreed-with Q-statements were (1) the PHR is a paper-based system, and (2) it is most effective to carry the PHR information in USB storage. CONCLUSION: Health information professionals agree that PHRs should be lifetime records, that they will be useful as more information is stored electronically, and that data security is paramount. To maximize the benefits of PHR, activation strategies should be developed and extended across disciplines and professionals so that patients begin to receive the benefits associate with using PHRs.

KimmeL, Z., Greenes, R. A., & Liederman, E. (2005). Personal health records. *Journal of Medical Practice Management, 21*(3), 147-152.

Nationwide, momentum is growing to provide patients with computer tools called personal health records (PHRs). These allow patients to participate in their own

healthcare management by viewing, editing, or discussing their own medical data. Historically, PHRs targeted consumers, but contemporary PHRs are increasingly aimed at providers and payers. This article reviews the types of PHRs that are currently available, discusses the PHR functionalities that offer the best value for a medical practice, and provides strategies for making purchasing decisions.

Lahteenmaki, J., Leppanen, J., & Kaijanranta, H. (2009). Interoperability of personal health records. *Conference Proceedings : ...Annual International Conference of the IEEE Engineering in Medicine and Biology Society., 2009*, 1726-1729.

doi:10.1109/IEMBS.2009.5333559

Personal Health Records (PHR's) and related services are emerging rapidly. Currently, most PHR's are isolated and do not communicate with other systems. Standards for interoperability exist, but they are oriented towards clinical applications. However, a substantial part of a typical PHR consists of non-clinical information such as a health diary. The present paper highlights the requirements related to exchanging non-clinical PHR information between services and shows how this information exchange can be accomplished. The approach utilizes a SOAP message for carrying the actual PHR content in a structure referred as Health Diary Entry (HDE) document. The HDE document provides mechanisms to bind the contents to external vocabularies and ontologies to achieve semantic interoperability. The approach was successfully tested in the context of an occupational health pilot, in which data contents from several health and wellness applications were merged into a common database.

Luo, G., Tang, C., & Thomas, S. B. (2011). Intelligent personal health record: Experience and open issues. *Journal of Medical Systems*, Mar 12, Epub ahead of print.

doi:10.1007/s10916-011-9674-5

Web-based personal health records (PHRs) are under massive deployment. To improve PHR's capability and usability, we previously proposed the concept of intelligent PHR (iPHR). By introducing and extending expert system technology and Web search technology into the PHR domain, iPHR can automatically provide users with personalized healthcare information to facilitate their daily activities of living. Our iPHR system currently provides three functions: guided search for disease information, recommendation of home nursing activities, and recommendation of home medical products. This paper discusses our experience with iPHR as well as the open issues, including both enhancements to the existing functions and potential new functions. We outline some preliminary solutions, whereas a main purpose of this paper is to stimulate future research work in the area of consumer health informatics.

Maloney, F. L., & Wright, A. (2010). USB-based Personal Health Records: An analysis of features and functionality. *International Journal of Medical Informatics*, 79(2), 97-111.

doi:10.1016/j.ijmedinf.2009.11.005

PURPOSE: To determine the features of commercially available USB-based Personal Health Records (PHR) devices, and compare the commercial state of the art to recommendations made by certification committees. **METHODS:** Thirteen USB-based PHRs were identified and analyzed based on data elements used and features provided. Marketing techniques used by the companies were also explored. **RESULTS:** Eight of the thirteen PHRs contained all seven clinical data elements (problems,

procedures, medications, providers, allergies, labs, immunizations), three were missing a single element and the remaining two lacked two elements. In the features analysis no single PHR contained all eight features (export data, import data, images, summary print out, emergency entry, teaching material available for problem, username and password supported, Mac-compatible), but two of the devices had seven of the eight features. Finally, scare tactics were used in marketing all but two of the PHR devices. CONCLUSION: While PHRs are very important in the health care field, at the present time, USB-based PHRs currently on the market appear to have deficiencies. Tethered or web-based PHRs may be a better option for consumers at present.

Markle Foundation. (2011). *CP8: Consumer obtainment and control of information: Health application terminology*. Retrieved April 28, 2012, from <http://www.markle.org/health/markle-common-framework/connecting-consumers/cp8>

The term "personal health records" is inadequate because of its emphasis on "records" as past information. To make sense of their health and health care, consumers likely want useful tools and convenient services more than mere records. Some prefer the term "personal health applications." However, we use the term PHR because it has become a term of art. This paper identifies six dimensions of consumer access and control in a networked PHR environment. The specific levels of consumer control may vary depending on the type of the Consumer Access Service and/or the PHR application in use.

New-age PHR comes with decision-support, multiple opportunities for DM. (2006). *Disease Management Advisor*, 12(12), 140-2, 133.

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

Oftedahl, G., & Marshall, M. (2010). The future of personal health records: A summary of a roundtable discussion. *Minnesota Medicine*, 93(7), 50-52. Retrieved from <http://www.minnesotamedicine.com/PastIssues/PastIssues2010/July2010/ClinicalOftedahlJuly2010.aspx>

In 2009, the Institute for Clinical Systems Improvement held a roundtable on personal health records (PHRs). Participants shared their thoughts about which features and functions are desired in a PHR, areas that need further exploration, and ways PHRs could make health care more efficient and effective. This article summarizes those discussions.

Personal health records: An emerging trend. (2008). *Journal of Oncology Practice*, 4(4), 200-202. doi:10.1200/JOP.0842508

While today PHRs seem far from the world of working oncology offices, that may change soon.

Pringle, S., & Lippitt, A. (2009). Interoperability of electronic health records and personal health records: Key interoperability issues associated with information exchange.

Journal of Healthcare Information Management, 23(3), 31-37.

As patients receive medical care, their clinical history may be tracked and recorded by multiple electronic systems developed by independent vendors. Medical providers might use electronic health record (EHR) software tailored to the needs of trained medical personnel, whereas patients may interact with personal health records (PHR). The purpose of this essay is to identify the key interoperability issues associated with the information exchange between these two types of systems and offer an approach for enhancing interoperability. This article is part of a series of unpublished essays titled *A Community View on How Personal Health Records Can Improve Patient Care and Outcomes in Many Healthcare Settings*, a collaborative project of Northern Illinois Physicians For Connectivity and the Coalition for Quality and Patient Safety of Chicagoland. For further information on how you can obtain copies of the complete work, contact the principle Dr. Stasia Kahn at Stash5@sbcglobal.net.

Randeree, E. (2009). Exploring technology impacts of Healthcare 2.0 initiatives.

Telemedicine Journal and e-Health, 15(3), 255-260. doi:10.1089/tmj.2008.0093

As Internet access proliferates and technology becomes more accessible, the number of people online has been increasing. Web 2.0 and the social computing phenomena (such as Facebook, Friendster, Flickr, YouTube, Blogger, and MySpace) are creating a new reality on the Web: Users are changing from consumers of Web-available information and resources to generators of information and content. Moving beyond telehealth and Web sites, the push toward Personal Health Records has emerged as a

new option for patients to take control of their medical data and to become active participants in the push toward widespread digitized healthcare. There is minimal research on the impact of Web 2.0 in healthcare. This paper reviews the changing patient-physician relationship in the Healthcare 2.0 environment, explores the technological challenges, and highlights areas for research.

Reti, S. R., Feldman, H. J., & Safran, C. (2009). Governance for personal health records.

Journal of the American Medical Informatics Association, 16(1), 14-17.

doi:10.1197/jamia.M2854

Personal health records (PHR) are a modern health technology with the ability to engage patients more fully in their healthcare. Despite widespread interest, there has been little discussion around PHR governance at an organizational level. We develop a governance model and compare it to the practices of some of the early PHR adopters, including hospitals and ambulatory care settings, insurers and health plans, government departments, and commercial sectors. Decision-making structures varied between organizations. Business operations were present in all groups, but patients were not represented in any of the governance structures surveyed. To improve patient-centered care, policy making for PHRs needs to include patient representation at a governance level.

Sensmeier, J. E. (2010). The journey toward a personal health record. *Nursing Management*,

41(2), 47-50. doi:10.1097/01.NUMA.0000368568.05221.5a

The purpose of this article is to define what a PHR is and describe the benefits of a PHR. It includes considerations for selection and implementation of a PHR.

Sequist, T. D., Zaslavsky, A. M., Colditz, G. A., & Ayanian, J. Z. (2011). Electronic patient messages to promote colorectal cancer screening: A randomized controlled trial.

Archives of Internal Medicine, 171(7), 636-641. doi:10.1001/archinternmed.2010.467

BACKGROUND: Colorectal cancer is a leading cause of cancer mortality, yet effective screening tests are often underused. Electronic patient messages and personalized risk assessments delivered via an electronic personal health record could increase screening rates. **METHODS:** We conducted a randomized controlled trial in 14 ambulatory health centers involving 1103 patients ranging in age from 50 to 75 years with an active electronic personal health record who were overdue for colorectal cancer screening. Patients were randomly assigned to receive a single electronic message highlighting overdue screening status with a link to a Web-based tool to assess their personal risk of colorectal cancer. The outcomes included colorectal cancer screening rates at 1 and 4 months. **RESULTS:** Screening rates were higher at 1 month for patients who received electronic messages than for those who did not (8.3% vs 0.2%, $P < .001$), but this difference was no longer significant at 4 months (15.8% vs 13.1%, $P = .18$). Of 552 patients randomized to receive the intervention, 296 (54%) viewed the message, and 47 (9%) used the Web-based risk assessment tool. Among 296 intervention patients who viewed the electronic message, risk tool users were more likely than nonusers to request screening examinations (17% vs 4%, $P = .04$) and to be screened (30% vs 15%, $P = .06$). One-fifth of patients (19%) using the risk assessment tool were estimated to have an above-average risk for colorectal cancer. **CONCLUSION:** Electronic messages to patients produce an initial increase in colorectal

cancer screening rates, but this effect is not sustained over time. TRIAL

REGISTRATION: clinicaltrials.gov Identifier: NCT01032746.

Siek, K. A., Ross, S. E., Khan, D. U., Haverhals, L. M., Cali, S. R., & Meyers, J. (2010). Colorado Care Tablet: The design of an interoperable Personal Health Application to help older adults with multimorbidity manage their medications. *Journal of Biomedical Informatics*, 43(5 Suppl), S22-6.

Medication errors are common and cause serious health issues during care transitions, particularly for older adults with multiple chronic conditions. In this paper, we discuss the design and evaluation of the Colorado Care Tablet, a Personal Health Application (PHA) that helps older adults and their lay caregivers manage their medication regimes during care transitions. We created a PHA that older adults with limited computing experience could easily use by designing an application based on their real world artifacts and workflows. Copyright Copyright 2010 Elsevier Inc. All rights reserved.

Simborg, D. W. (2010). Consumer empowerment versus consumer populism in healthcare IT. *Journal of the American Medical Informatics Association*, 17(4), 370-372.

Institutions, providers, and informaticians now encourage healthcare consumers to take greater control of their own healthcare needs through improved health and wellness activities, internet-based education and support groups, and personal health records. The author believes that "untethering" all of these activities from provider-based record systems has introduced a form of unhealthy consumer populism.

Conversely, integrating these activities in a coordinated manner can sustain both consumer empowerment and consumer well-being.

Slagle, J. M., Gordon, J. S., Harris, C. E., Davison, C. L., Culpepper, D. K., Scott, P., & Johnson, K.

B. (2010). MyMediHealth - designing a next generation system for child-centered medication management. *Journal of Biomedical Informatics*, 43(5 Suppl), S27-31.

BACKGROUND: The last mile of the medication use system requires tools to help patients comply with medication administration rules and monitor for side effects.

Personal health records (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 healthcare 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. **DESIGN**

APPROACH: This project employed user-centered design to identify requirements for a child-centered medication management system. We collected information through site visits, facilitated group discussions, and iterative design sessions with adult caregivers.

Once design requirements were articulated and validated, we constructed an initial prototype medication scheduler, which was evaluated by 202 parents using scripted

activities completed using an online interactive prototype. The results of this analysis

informed the development of a working prototype. **STATUS:** We 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.

IMPLICATIONS: 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.

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Smolij, K., & Dun, K. (2006). Patient health information management: Searching for the right model. *Perspectives in Health Information Management*, 3, 10.

Accurate and timely health information is a crucial element in the medical decision making process during a medical encounter. Inadequate or misleading patient health information can lead to medical errors, inaccurate decision making, and increased cost. Providing physicians with access to every detail of a patient's medical history is difficult. Striking the balance between adequate and effective amounts of information is difficult. The Personal Health Record and Continuity of Care Record have emerged as concepts to support that balance. This paper reviews recently published literature on (1) approaches to personal health information management, (2) distinctions between terms and definitions describing patient health information, its format, its availability, and its accessibility, (3) guidelines, studies, or standards to support the rationale of patient information data elements that should be available to the provider for any medical encounter, and (4) identification of the most important needs for patient health information that should be addressed. The purpose of the review is to clarify the benefits and detriments of the different approaches as well as to provide some recommendations for the right model of patient health information management, focusing on the idea of the appropriate health information being available when needed.

Tague, R., Maeder, A. J., & Nguyen, Q. V. (2010). Time-based interactive visualisation of vital signs. *Studies in Health Technology and Informatics*, 161, 169-178.

Physiological vital signs are important factors for clinical processes like tele-assessment, tele-monitoring and tele-treatment of patients. Records of patient vital signs over time are complex to understand without proper visualisation and data analysis aids. We present a model for interactively visualising vital signs in patient data histories, as used for remote chronic disease management. Our model allows simultaneous access to all vital signs records for the patient along a time-based axis. Clinicians and other health carers can then apply generalisation and refinement 'lenses' in a multi-layering visualisation mechanism to examine records further over single or multiple time sessions. The model also includes rule-based decisions for issuing notifications, when expected limits are exceeded.

Tang, P. C., Ash, J. S., Bates, D. W., Overhage, J. M., & Sands, D. Z. (2006). Personal health records: Definitions, benefits, and strategies for overcoming barriers to adoption. *Journal of the American Medical Informatics Association*, 13(2), 121-126.

doi:10.1197/jamia.M2025

Recently there has been a remarkable upsurge in activity surrounding the adoption of personal health record (PHR) systems for patients and consumers. The biomedical literature does not yet adequately describe the potential capabilities and utility of PHR systems. In addition, the lack of a proven business case for widespread deployment hinders PHR adoption. In a 2005 working symposium, the American Medical Informatics Association's College of Medical Informatics discussed the issues surrounding personal health record systems and developed recommendations for

PHR-promoting activities. Personal health record systems are more than just static repositories for patient data; they combine data, knowledge, and software tools, which help patients to become active participants in their own care. When PHRs are integrated with electronic health record systems, they provide greater benefits than would stand-alone systems for consumers. This paper summarizes the College Symposium discussions on PHR systems and provides definitions, system characteristics, technical architectures, benefits, barriers to adoption, and strategies for increasing adoption.

Tang, P. C., & Lee, T. H. (2009). Your doctor's office or the Internet? Two paths to personal health records. *New England Journal of Medicine*, 360(13), 1276-1278.

doi:10.1056/NEJMp0810264

The authors provide a case study demonstrating the need for a PHR. They then go onto contrast the benefits of a stand alone vs tethered PHR. Tethered PHRs can offer patients as much access to data, scheduling resources, and communication among members of the health care team as providers are willing to permit. Users of integrated PHRs have demonstrated that creating shared records for patients and their health care team can enhance patients' ability to become active partners in their own health care.

Tenforde, M., Jain, A., & Hickner, J. (2011). The value of personal health records for chronic disease management: What do we know? *Family Medicine*, 43(5), 351-354.

BACKGROUND AND OBJECTIVES: Electronic personal health records (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, we explore the evidence for the value of PHRs in chronic disease management. METHODS: We used a comprehensive review of MEDLINE articles published in English between January 2000 and September 2010 on personal health records and related search terms. RESULTS: Few published articles have described PHR programs designed for use in chronic disease management or PHR adoption and attitudes in the context of chronic disease management. Only three prospective randomized trials have evaluated the benefit of PHR use in chronic disease management, all in diabetes care. These trials showed small improvements in some but not all diabetes care measures. All three trials involved additional interventions, making it difficult to determine the influence of patient PHR use in improved outcomes. CONCLUSIONS: The evidence remains sparse to support the value of PHR use for chronic disease management. With the current policy focus on meaningful use of electronic and personal health records, it is crucial to investigate and learn from new PHR products so as to maximize the clinical value of this tool.

Tuomainen, M., & Mykkanen, J. (2011). Reference architecture of application services for personal wellbeing information management. *Studies in Health Technology and Informatics*, 169, 98-102.

Personal information management has been proposed as an important enabler for

individual empowerment concerning citizens' wellbeing and health information. In the MyWellbeing project in Finland, a strictly citizen-driven concept of "Coper" and related architectural and functional guidelines have been specified. We present a reference architecture and a set of identified application services to support personal wellbeing information management. In addition, the related standards and developments are discussed.

Varroud-Vial, M. (2011). Improving diabetes management with electronic medical records.

Diabetes & Metabolism, 37(Suppl 4), S48-52. doi:10.1016/S1262-3636(11)70965-X

Most primary-care physicians have adopted electronic medical records (EMRs) for the management of patients in ambulatory care. Observational trials suggest that the use of EMRs improves the achievement of the recommended standards of diabetes care and intermediate outcomes. A French group of general practitioners has shown, in a randomized controlled trial of diabetes care, the beneficial effects of a follow-up module integrated into an EMR. Electronic reminders, eHealth technology and e-mail messaging to patients integrated into the EMR have also been reported to have a beneficial effect on diabetes care. Some recommendations have been devised for the meaningful use of EMRs to improve the process and, possibly, intermediate outcomes of diabetes care as well. Another potential benefit to consider is the extraction and aggregation of data to create diabetes registers. Large regional and national diabetes registers have been set up in the US and Europe for various purposes, including patient recall, description of care patterns and outcomes, improvement of practices, drug safety, observational research and retrospective trials. In France, the government initiative towards an Internet-based personal health record (PHR) provides an

appropriate framework for implementing and sharing the information needed to improve diabetes care, such as electronic summaries of health information, personalized health plans (PHPs), and standardized and structured hospital-discharge forms. All of these materials can be generated from EMRs. The widespread and optimized use of EMRs for diabetes care with links to the national diabetes register and the capacity to supply PHRs are major considerations. Achieving these goals requires a common initiative comprising primary care and diabetes scientific societies in cooperation with diabetes patients' associations.

VA's web-based personal health record can be a model for others. (2005). *Internet Healthcare Strategies*, 7(4), 8-10.

The VA is a leader in development of PHRs. In this article the pitfalls of not having a PHR demonstrate the benefits that a PHR can help overcome. Often patients don't tell their whole story and often most patients move. The web-based electronic world connects people and PHRs that are web-enabled to improve documentation and communication of personal health issues.

Vincent, A., Kaelber, D. C., Pan, E., Shah, S., Johnston, D., & Middleton, B. (2008). A patient-centric taxonomy for personal health records (PHRs). *AMIA Annual Symposium Proceedings, 2008*, 763-767.

Today, the nascent field of personal health records (PHRs) lacks a comprehensive taxonomy that encompasses the full range of PHRs currently in existence and what may be possible. The Center for Information Technology Leadership (CITL) has created a taxonomy that broadly defines a PHR as having both an infrastructure component,

which allows for data viewing and sharing, and an application component, allowing for self-management and information exchange. The taxonomy also accounts for different PHR architectures provider, payer, third-party, or interoperable. This comprehensive taxonomy may help to define the field of PHRs and provide a framework for assessing PHR value.

Wagner, P. J., Dias, J., Howard, S., Kintziger, K. W., Hudson, M. F., Seol, Y. H., & Sodomka, P. (2012). Personal health records and hypertension control: A randomized trial. *Journal of the American Medical Informatics Association*, 2012 Jan 12, Epub ahead of print. doi:10.1136/amiajnl-2011-000349

Purpose: To examine the impact of a personal health record (PHR) in patients with hypertension measured by changes in biological outcomes, patient empowerment, patient perception of quality of care, and use of medical services. Methods A cluster-randomized effectiveness trial with PHR and no PHR groups was conducted in two ambulatory clinics. 453 of 1686 (26.4%) patients approached were included in the analyses. A PHR tethered to the patient's electronic medical record (EMR) was the primary intervention and included security measures, patient control of access, limited transmission of EMR data, blood pressure (BP) tracking, and appointment assistance. BP was the main outcome measure. Patient empowerment was assessed using the Patient Activation Measure and Patient Empowerment Scale. Quality of care was assessed using the Clinician and Group Assessment Score (CAHPS) and the Patient Assessment of Chronic Illness Care. Frequency of use of medical services was self-reported. Results No impact of the PHR was observed on BP, patient activation, patient perceived quality, or medical utilization in the intention-to-treat analysis. Sub-analysis

of intervention patients self-identified as active PHR users (25.7% of those with available information) showed a 5.25-point reduction in diastolic BP. Younger age, self-reported computer skills, and more positive provider communication ratings were associated with frequency of PHR use. Conclusions Few patients provided with a PHR actually used the PHR with any frequency. Thus simply providing a PHR may have limited impact on patient BP, empowerment, satisfaction with care, or use of health services without additional education or clinical intervention designed to increase PHR use. Clinical trial registration number <http://ClinicalTrials.gov> Identifier: NCT01317537.

Wang, C. J., & Huang, A. T. (2012). Integrating technology into health care: What will it take?

JAMA, 307(6), 569-570. doi:10.1001/jama.2012.102

Purpose To examine the impact of a personal health record (PHR) in patients with hypertension measured by changes in biological outcomes, patient empowerment, patient perception of quality of care, and use of medical services.

Methods A cluster-randomized effectiveness trial with PHR and no PHR groups was conducted in two ambulatory clinics. 453 of 1686 (26.4%) patients approached were included in the analyses. A PHR tethered to the patient's electronic medical record (EMR) was the primary intervention and included security measures, patient control of access, limited transmission of EMR data, blood pressure (BP) tracking, and appointment assistance. BP was the main outcome measure. Patient empowerment was assessed using the Patient Activation Measure and Patient Empowerment Scale. Quality of care was assessed using the Clinician and Group Assessment Score (CAHPS) and the Patient Assessment of Chronic Illness Care.

Frequency of use of medical services was self-reported.

Results No impact of the PHR was observed on BP, patient activation, patient perceived quality, or medical utilization in the intention-to-treat analysis. Sub-analysis of intervention patients self-identified as active PHR users (25.7% of those with available information) showed a 5.25-point reduction in diastolic BP. Younger age, self-reported computer skills, and more positive provider communication ratings were associated with frequency of PHR use. Conclusions Few patients provided with a PHR actually used the PHR with any frequency. Thus simply providing a PHR may have limited impact on patient BP, empowerment, satisfaction with care, or use of health services without additional education or clinical intervention designed to increase PHR use.

Weinert, C., Cudney, S., & Kinion, E. (2010). Development of My Health Companion to enhance self-care management of chronic health conditions in rural dwellers. *Public Health Nursing (Boston, Mass.)*, 27(3), 263-269. doi:10.1111/j.1525-1446.2010.00852.x

Appropriate self-management support is needed to help individuals and their families meet the challenges of living with chronic health conditions. Such support is characterized by productive interactions between informed, active individuals, and their health care providers. The purposes of this paper are to describe the challenges to achieving self-management support and a tool, My Health Companion (MHC), which was developed to meet that challenge. The MHC is a paper personal health record designed to help rural women with chronic health conditions to better manage and understand their health information. The selection of content for the MHC was based on the literature, input from health care experts, and chronically ill individuals, and its

development incorporated principles of personal health record and clear communication. The MHC was anecdotally shown to be useful to rural women with chronic health conditions in preparing for and enhancing their visits with health care providers. As a source of information, the MHC had potential for: being beneficial to providers in recommending appropriate treatment; contributing to more informed health decision making by ill individuals; and serving as a vehicle for the establishment of more productive interactions that contributed to the achievement of true client-provider partnerships in health care.

Weitzman, E. R., Kaci, L., Quinn, M., & Mandl, K. D. (2011). Helping high-risk youth move through high-risk periods: Personally controlled health records for improving social and health care transitions. *Journal of Diabetes Science and Technology*, 5(1), 47-54.

Retrieved from

<http://www.ncbi.nlm.nih.gov.ezp1.lib.umn.edu/pmc/articles/PMC3045245/>

BACKGROUND: New patient-centered information technologies are needed to address risks associated with health care transitions for adolescents and young adults with diabetes, including systems that support individual and structural impediments to self- and clinical-care. METHODS: We describe the personally controlled health record (PCHR) system platform and its key structural capabilities and assess its alignment with tenets of the chronic care model (CCM) and the social-behavioral and health care ecologies within which adolescents and young adults with diabetes mature. RESULTS: Configured as Web-based platforms, PCHRs can support a new class of patient-facing applications that serve as monitoring and support systems for adolescents navigating complex social, developmental, and health care transitions. The approach can enable

supportive interventions tailored to individual patient needs to boost adherence, self-management, and monitoring. CONCLUSIONS: The PCHR platform is a paradigm shift for the organization of health information systems and is consistent with the CCM and conceptualizations of patient- and family-centered care for diabetes. Advancing the approach augers well for improvement around health care transitions for youth and also requires that we address (i) structural barriers impacting diabetes care for maturing youth; (ii) challenges around health and technology literacy; (iii) privacy and confidentiality issues, including sharing of health information within family and institutional systems; and (iv) needs for evaluation around uptake, impacts, and outcomes.

Wiler, J. L., Gentle, C., Halfpenny, J. M., Heins, A., Mehrotra, A., Mikhail, M. G., & Fite, D.

(2010). Optimizing emergency department front-end operations. *Annals of Emergency Medicine*, 55(2), 142-160.e1. doi:10.1016/j.annemergmed.2009.05.021

As administrators evaluate potential approaches to improve cost, quality, and throughput efficiencies in the emergency department (ED), "front-end" operations become an important area of focus. Interventions such as immediate bedding, bedside registration, advanced triage (triage-based care) protocols, physician/practitioner at triage, dedicated "fast track" service line, tracking systems and whiteboards, wireless communication devices, kiosk self check-in, and personal health record technology ("smart cards") have been offered as potential solutions to streamline the front-end processing of ED patients, which becomes crucial during periods of full capacity, crowding, and surges. Although each of these operational improvement strategies has been described in the lay literature, various reports exist in the academic literature

about their effect on front-end operations. In this report, we present a review of the current body of academic literature, with the goal of identifying select high-impact front-end operational improvement solutions.

Wright, A., Poon, E. G., Wald, J., Feblowitz, J., Pang, J. E., Schnipper, J. L., . . . Middleton, B. (2012). Randomized controlled trial of health maintenance reminders provided directly to patients through an electronic PHR. *Journal of General Internal Medicine*, 27(1), 85-92. doi:10.1007/s11606-011-1859-6

BACKGROUND: Provider and patient reminders can be effective in increasing rates of preventive screenings and vaccinations. However, the effect of patient-directed electronic reminders is understudied. **OBJECTIVE:** To determine whether providing reminders directly to patients via an electronic Personal Health Record (PHR) improved adherence to care recommendations. **DESIGN:** We conducted a cluster randomized trial without blinding from 2005 to 2007 at 11 primary care practices in the Partners HealthCare system. **PARTICIPANTS:** A total of 21,533 patients with access to a PHR were invited to the study, and 3,979 (18.5%) consented to enroll.

INTERVENTIONS: Patients in the intervention arm received health maintenance (HM) reminders via a secure PHR "eJournal," which allowed them to review and update HM and family history information. Patients in the active control arm received access to an eJournal that allowed them to input and review information related to medications, allergies and diabetes management. **MAIN MEASURES:** The primary outcome measure was adherence to guideline-based care recommendations. **KEY RESULTS:** Intention-to-treat analysis showed that patients in the intervention arm were significantly more likely to receive mammography (48.6% vs 29.5%, $p = 0.006$) and influenza

vaccinations (22.0% vs 14.0%, $p = 0.018$). No significant improvement was observed in rates of other screenings. Although Pap smear completion rates were higher in the intervention arm (41.0% vs 10.4%, $p < 0.001$), this finding was no longer significant after excluding women's health clinics. Additional on-treatment analysis showed significant increases in mammography ($p = 0.019$) and influenza vaccination ($p = 0.015$) for intervention arm patients who opened an eJournal compared to control arm patients, but no differences for any measure among patients who did not open an eJournal. CONCLUSIONS: Providing patients with HM reminders via a PHR may be effective in improving some elements of preventive care.

Wu, Y. H., Li, Y. Z., & Li, Y. C. (2009). Between personal health record website and portable medical health record: An online data transformation interface. *Studies in Health Technology and Informatics*, 146, 728.

Web-based Personal health record recently brought out the whole world attention by two famous vendors involved in this battle field. The convenience and ubiquity of user-end data management influence the user's will greatly. This study is based on the idea of easy data transfer from the portal device to the web-based personal health record, and further more this can promote the use of personal health record and assist more people manage their own health.

Wynia, M., & Dunn, K. (2010). Dreams and nightmares: Practical and ethical issues for patients and physicians using personal health records. *Journal of Law, Medicine & Ethics*, 38(1), 64-73. doi:10.1111/j.1748-720X.2010.00467.x

Electronic health records for patients, personal health records (PHRs), have become

increasingly popular among policy makers and purchasers, but uptake among patients and physicians has been relatively slow. PHRs have varying uses that might make them more or less appealing to different stakeholders. The three core uses for PHRs - promoting communication, data use, and patient responsibility - each raises a set of potential practical and financial dilemmas. But some ethical concerns are also at play, some of which are rarely recognized as values-based barriers to the use of PHRs. Recognizing these ethical issues, and addressing them explicitly in PHR design and policy making, would help PHRs to achieve their promise.

Wynia, M. K., Torres, G. W., & Lemieux, J. (2011). Many physicians are willing to use patients' electronic personal health records, but doctors differ by location, gender, and practice. *Health Affairs (Project Hope)*, 30(2), 266-273. doi:10.1377/hlthaff.2010.0342

Electronic personal health records could become important tools for patients to use in managing and monitoring their health information and communicating with clinicians. 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, we found that although 64 percent have never used a patient's electronic personal health record, 42 percent 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 percent versus 46 percent). 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.

Yaqub, E., & Barroso, A. (2010). Distributed guidelines (DiG): A software framework for extending automated health decision support to the general population. *Perspectives in Health Information Management*, 7, 1b.

This article presents a framework and methodology to create personal health record (PHR) systems able to transform raw health data into meaningful information for the general population. By bridging the semantic gap between an individual and his or her health data, it is expected that better care will ensue through consumer empowerment. An important challenge for the realization of this vision is the lack of available expert knowledge in a format that is concomitantly easy to codify, share, and be used by the general population. To address this challenge, we developed a novel approach to encode expert knowledge into machine-interpretable, reusable components called "consumer guidelines." Once encoded, guidelines are easily shared, extended, and modified. These guidelines can exist as distributed documents on the Internet and be executed by our processing engine (Health-Guru) to provide an individual with personalized assessment against various health risks based on the evidence data stored in a PHR.

Engaging Consumers: Annotated Bibliography

Anoshiravani, A., Gaskin, G., Kopetsky, E., Sandborg, C., & Longhurst, C. A. (2011).

Implementing an interoperable personal health record in pediatrics: Lessons learned at an academic children's hospital. *Journal of Participatory Medicine*, 3, e30.

This paper describes the development of an innovative health information technology creating a bidirectional link between the electronic medical record (EMR) of an academic children's hospital and a commercially available, interoperable personal health record (PHR). The goal of the PHR project has been to empower pediatric patients and their families to play a more active role in understanding, accessing, maintaining, and sharing their personal health information to ultimately improve health outcomes. The most notable challenges proved more operational and cultural than technological. Our experience demonstrates that an interoperable PHR is technically and culturally achievable at a pediatric academic medical center.

Recognizing the complex social, cultural, and organizational contexts of these systems is important for overcoming barriers to a successful implementation.

Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbin, K. A., & Straus, S. E. (2011). Personal health records: A scoping review. *Journal of the American Medical Informatics Association*, 18(4), 515-522. doi:10.1136/amiajnl-2011-000105

Electronic personal health record systems (PHRs) support patient centered healthcare by making medical records and other relevant information accessible to patients, thus assisting patients in health self-management. We reviewed the literature on PHRs including design, functionality, implementation, applications, outcomes, and benefits.

We found that, because primary care physicians play a key role in patient health, PHRs are likely to be linked to physician electronic medical record systems, so PHR adoption is dependent on growth in electronic medical record 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.

Benhamou, P. Y. (2011). Improving diabetes management with electronic health records and patients' health records. *Diabetes & Metabolism*, 37(Suppl 4), S53-6.

doi:10.1016/S1262-3636(11)70966-1

The lack of patient engagement and clinical inertia both contribute to suboptimal diabetes care. However, both obstacles are amenable to informatics- and Internet-based interventions. The use of electronic medical records (EMRs) is now established as being useful for improving diabetes care. Intelligent records that integrate computerized decision-support systems are now able to recommend care protocols tailored to risk levels. Web-based personal health record (PHR) systems, shared with healthcare providers, could also provide added value by promoting self-management of the behaviours related to diabetes. These Web-based programmes include patients' access to EMRs, uploading of glucose monitoring results, a glucose diary, secure e-mail with providers, manual or automated feedback on blood glucose readings and other risk factors, an educational website, and an online diary for entering personal

information on exercise, diet and medication. The integration of Web-based patients' systems into the EMR used by physicians is the next frontier. In addition, the input from "smartphones" that are able to provide real-time support to patients could contribute to the reorganization of diabetes care. Convincing data on HbA(1c) improvements with such systems are available for type 2 diabetes, but are still equivocal for type 1 diabetes. Obstacles include patients' compliance with the technology, their ergonomic design and the need to reimburse providers for their care. Designing appropriate electronic tools and tailoring them to the conditions in France merits our attention.

Bonander, J., & Gates, S. (2010). Public health in an era of personal health records:

Opportunities for innovation and new partnerships. *Journal of Medical Internet Research*, 12(3), e33. doi:10.2196/jmir.1346

In the near future, citizens will be able to control and manage their own health information through electronic personal health record systems and tools. The clinical benefits of this innovation, such as cost savings, error reduction, and improved communication, have been discussed in the literature and public forums, as have issues related to privacy and confidentiality. Receiving little attention are the benefits these will have for public health. The benefits and potential for innovation are broad and speak directly to core public health functions such as health monitoring, outbreak management, empowerment, linking to services, and research. Coupled with this is a new relationship with citizens as key partners in protecting and promoting the public's health.

Botts, N. E., Horan, T. A., & Thoms, B. P. (2011). HealthATM: Personal health

cyberinfrastructure for underserved populations. *American Journal of Preventive Medicine*, 40(5 Suppl 2), S115-22. doi:10.1016/j.amepre.2011.01.016

BACKGROUND: There is an opportunity for personal health record (PHR) systems to play a vital role in fostering health self-management within underserved populations.

If properly designed and promoted, it is possible that patients will use PHRs to become more empowered in taking an active role toward managing their health needs.

PURPOSE: This research examines the potential of a cyberinfrastructure-based PHR to encourage patient activation in health care, while also having population health

implications. **METHODS:** A multi-phased, iterative research approach was used to design and evaluate a PHR system called HealthATM, which utilizes services from a cloud computing environment. These services were integrated into an ATM-style interface aimed at providing a broad range of health consumers with the ability to

manage health conditions and encourage accomplishment of health goals. **RESULTS:**

Evaluation of the PHR included 115 patients who were clients of several free clinics in Los Angeles County. The majority of patients perceived ease of use (74%) and

confidence (73%) in using the HealthATM system, and thought they would like to use it frequently (73%). Patients also indicated a belief in being responsible for their own

health. However, fewer felt as though they were able to maintain necessary life

changes to improve their health. **CONCLUSIONS:** Findings from the field tests suggest that PHRs can be a beneficial health management tool for underserved populations. In

order for these types of tools to be effective within safety-net communities, they must

be technically accessible and provide meaningful opportunities to increase patient engagement in their health care.

Brennan, P. F., Casper, G., Downs, S., & Aulakh, V. (2009). Project HealthDesign: Enhancing action through information. *Studies in Health Technology and Informatics*, 146, 214-218.

Project HealthDesign is a country-wide initiative in the United States designed to stimulate innovation in personal health records (PHRs). Nine grantee teams engaged in an 18-month long design and prototyping process. Two teams addressed the needs of children and adolescents; three created novel approaches to help adults prevent or manage metabolic syndrome; three groups employed interface innovations to assist patients with chronic care management and one team devised a novel calendaring system to assist patients undergoing complex medical/surgical treatments to integrate care processes into their daily lives. These projects not only included development and testing of novel personal health records applications, but also served as the starting point to specify and implement a common technical core platform. The project advanced PHR development in two key ways: intensive user-centered design and a development architecture that separates applications of PHRs from the infrastructure that supports them. The initiative also allowed systematic investigation of significant ethical, legal and social issues, including how privacy considerations are changed when information technology innovations are used in the home and the rebalancing of the authority structure of health care decision making when patient-centered approaches guide the design of PHRs.

Buettner, K., & Fadem, S. Z. (2008). The internet as a tool for the renal community. *Advances in Chronic Kidney Disease*, 15(1), 73-82. doi:10.1053/j.ackd.2007.10.002

The Internet has impacted health care. With the introduction of the personal health record (PHR), patients have an opportunity to track their physician visits, medications, and laboratory values online in a pleasant and informative learning environment. The PHR is a secure, online, Internet-accessible method of storing and easily retrieving health information about one's medical history, physician visits, laboratory values, and medications. The American Association of Kidney Patients (AAKP) has taken the leadership role in developing a PHR for patients of the kidney community. There are several barriers that patients experience when using the Web for health resources. These include inaccurate or self-serving information and marketing statements that can be misleading and dangerous. Poorly written or inappropriate information for patients can be problematic, as can an abundance of extraneous information. For the most part, the public often has no way to judge what is and is not credible based on the context of the article alone. This article gives the reader a review of several Web resources that are available for patients and also for renal professionals. They are largely from large nonprofit organizations like the AAKP, National Kidney Foundation, Medical Education Institute, American Society of Nephrology, or The Nephron Information Center (nephron.com). This article also reviews sites from The National Kidney Disease Education Program, Hypertension-Dialysis and Clinical Nephrology, National Institute of Diabetes and Digestive and Kidney Diseases, and DaVita.

Burrington-Brown, J., & Friedman, B. (2005). Educating the public about personal health records. *Journal of AHIMA*, 76(9), 94-95.

Interview on how one man made presentations about PHRs within the community.

Chen, Y. (2010). The role of patients in transiting personal health information: A field study. *Studies in Health Technology and Informatics*, 160(Pt 1), 3-7.

Recent consumer health informatics initiatives advocate individual access and management of personal medical records. However, little is known regarding the impact of personal access of health information on clinical practice. This paper introduces a field study investigating the usage patterns of personal health records in medical consultations. The self-managed records provide patients with a strong sense of ownership and control over their own health information. Personal medical records have been used primarily for transiting information among different providers. This behavior changed patient-provider communication into a records sharing. Doing so effectively eliminated the potential errors in the verbal reporting process. This study indicates that patients can be effective contributors to their own health and suggest the design of health information systems to rethink the role of patients in the healthcare process and shift the responsibility of healthcare to the patients' side.

Chira, P., Nugent, L., Miller, K., Park, T., Donahue, S., Soni, A., . . . Sandborg, C. (2010). Living Profiles: design of a health media platform for teens with special healthcare needs. *Journal of Biomedical Informatics*, 43(5 Suppl), S9-12. doi:10.1016/j.jbi.2010.05.008

Living Profiles is a health media platform in development that aggregates multiple data flows to help teens with special healthcare needs (SHCN), particularly with regard to

self-management and independence. A teen-oriented personal health record (PHR) incorporates typical teen behaviors and attitudes about health and wellness, encompasses how teens perceive and convey quality of life, and aligns with data related to their chronic medical condition. We have conceived a secure personalized user interface called the Quality of Life Timeline, which will assist with the transition from pediatric care to an adult provider through modules that include a mood meter, reminder device, and teleport medicine. With this personalized PHR, teens with SHCN can better understand their condition and its effects on daily activities and life goals and vice versa; additionally, use of this PHR allows for better information sharing and communication between providers and patients. The use of a teen-oriented tool such as Living Profiles can impact teens' overall quality of life and disease self-management, important attributes for a successful transition program.

DeTora, G., & Linkon, N. (2009). The new age of healthcare communications. *Marketing Health Services, 29*(3), 23-27.

The purpose of this article is to describe the competitive market edge for hospitals who provide patient portals. It summarizes patient expectations and willingness to use portions of PHR. There is a table displaying what parts of a PHR have been deployed by various systems.

Dolan, M., Wolter, J., Nielsen, C., & Burrington-Brown, J. (2009). Consumer health informatics: is there a role for HIM professionals? *Perspectives in Health Information Management, 6*, 1-10.

This paper describes possible roles that HIM professionals can develop and fill to

support consumers in the population of and interpretation of PHR data. There is information on the concerns from providers about PHR access by patients and also some information cited about health literacy and how that impacts the consumers ability to fully utilize a PHR.

Ferguson, G., Quinn, J., Horwitz, C., Swift, M., Allen, J., & Galescu, L. (2010). Towards a Personal Health Management Assistant. *Journal of Biomedical Informatics*, 43(5 Suppl), S13-6. doi:10.1016/j.jbi.2010.05.014

We describe design and prototyping efforts for a Personal Health Management Assistant for heart failure patients as part of Project HealthDesign. An assistant is more than simply an application. An assistant understands what its users need to do, interacts naturally with them, reacts to what they say and do, and is proactive in helping them manage their health. In this project, we focused on heart failure, which is not only a prevalent and economically significant disease, but also one that is very amenable to self-care. Working with patients, and building on our prior experience with conversational assistants, we designed and developed a prototype system that helps heart failure patients record objective and subjective observations using spoken natural language conversation. Our experience suggests that it is feasible to build such systems and that patients would use them. The system is designed to support rapid application to other self-care settings.

Fonda, S. J., Kedziora, R. J., Vigersky, R. A., & Bursell, S. E. (2010). Combining iGoogle and personal health records to create a prototype personal health application for diabetes self-management. *Telemedicine Journal and e-Health*, 16(4), 480-489.

doi:10.1089/tmj.2009.0122

OBJECTIVE: The aim of this project is to create a prototype for a personal health application (PHA) for patients (i.e., consumers) with diabetes by employing a user-centered design process. This article describes the design process for and resulting architecture, workflow, and functionality of such a PHA. **MATERIALS AND METHODS:** For the design process, we conducted focus groups with people who have diabetes (n = 21) to ascertain their needs for a PHA. We then developed a prototype in response to these needs, and through additional focus groups and step-by-step demonstrations for people with diabetes as well as healthcare providers, we obtained feedback about the prototype. The feedback led to changes in the PHA's presentation and function. **RESULTS:** 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 those 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. **CONCLUSIONS:** A user-centered design process resulted in a PHA that uses technology that is publicly available, 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.

Fonda, S. J., Kedziora, R. J., Vigersky, R. A., & Bursell, S. E. (2010). Evolution of a web-based, prototype Personal Health Application for diabetes self-management. *Journal of Biomedical Informatics*, 43(5 Suppl), S17-21. doi:10.1016/j.jbi.2010.05.006

Behaviors carried out by the person with diabetes (e.g., healthy eating, physical activity, judicious use of medication, glucose monitoring, coping and problem-solving, regular clinic visits, etc.) are of central importance in diabetes management. To assist with these behaviors, we developed a prototype PHA for diabetes self-management that was based on User-Centered Design principles and congruent with the anticipatory vision of Project Health Design (PHD). This article presents aspects of the prototype PHA's functionality as conceived under PHD and describes modifications to the PHA now being undertaken under new sponsorship, in response to user feedback and timing tests we have performed. In brief, the prototype Personal Health Application (PHA) receives data on the major diabetes management domains from a Personal Health Record (PHR) and analyzes and provides feedback based on clinically vetted educational content. The information is presented within "gadgets" within a portal-based website. The PHR used for the first implementation was the Common Platform developed by PHD. Key changes include a re-conceptualization of the gadgets by topic areas originally defined by the American Association of Diabetes Educators, a refocusing on low-cost approaches to diabetes monitoring and data entry, and synchronization with a new PHR, Microsoft(R) HealthVault.

Forsyth, R., Maddock, C. A., Iedema, R. A., & Lassere, M. (2010). Patient perceptions of carrying their own health information: approaches towards responsibility and playing an active role in their own health - implications for a patient-held health file. *Health*

Expectations, 13(4), 416-426. doi:10.1111/j.1369-7625.2010.00593.x; 10.1111/j.1369-7625.2010.00593.x

OBJECTIVE: To elicit patients' views on whether they could contribute to improvements in their care by carrying their own health information to clinician encounters; and to consider the implications for the development of a patient-held health file (PHF). **BACKGROUND:** Increasing rates of chronic disease lead to health care being delivered by multiple care providers often at distributed geographic locations. As a way of increasing the availability of patient information to care providers our project will trial a PHF. Patients carry these files to doctors' appointments where clinicians record data for other doctors or the patient. Increasing the availability of patient information is anticipated to enhance the safety and quality of care delivery and improve health outcomes. **STUDY DESIGN:** Qualitative semi-structured interviews were conducted with 10 patients. Participants were evenly distributed in terms of gender, aged 60 years or greater and visited at least two specialists and one general practitioner. **FINDINGS:** In this exploratory study, patients who were currently active in decision making about their own health already recorded some health information. They were receptive to carrying their information and thought they should take some responsibility for their health. Patients who were more passive in making decisions about their health did not perceive a need to carry their own information and felt that their doctors communicated adequately. **CONCLUSION:** Patient-held health files provide an opportunity for patients to access their health information. Such files have the potential to improve health outcomes for patients who adopt both active and

passive roles in relation to their own health and engaging with their health information.

Frost, J. H., & Massagli, M. P. (2008). 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*, 10(3), e15.

doi:10.2196/jmir.1053

BACKGROUND: This project investigates the ways in which patients respond to the shared use of what is often considered private information: personal health data.

There is a growing demand for patient access to personal health records. The predominant model for this record is a repository of all clinically relevant health information kept securely and viewed privately by patients and their health care providers. While this type of record does seem to have beneficial effects for the patient-physician relationship, the complexity and novelty of these data coupled with the lack of research in this area means the utility of personal health information for the primary stakeholders-the patients-is not well documented or understood. **OBJECTIVE:**

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. We begin this paper by describing the components and design of the online community. We then identify and analyze how users of this platform reference personal health information within patient-to-patient dialogues. **METHODS:** Patients diagnosed with amyotrophic lateral sclerosis (ALS) post data on their current treatments, symptoms, and outcomes. These data are displayed graphically within

personal health profiles and are reflected in composite community-level symptom and treatment reports. Users review and discuss these data within the Forum, private messaging, and comments posted on each other's profiles. We analyzed member communications that referenced individual-level personal health data to determine how patient peers use personal health information within patient-to-patient exchanges. RESULTS: Qualitative analysis of a sample of 123 comments (about 2% of the total) posted within the community revealed a variety of commenting and questioning behaviors by patient members. Members referenced data to locate others with particular experiences to answer specific health-related questions, to proffer personally acquired disease-management knowledge to those most likely to benefit from it, and to foster and solidify relationships based on shared concerns. CONCLUSIONS: 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.

Gordon, J. (2011). Educating the patient: challenges and opportunities with current technology. *Nursing Clinics of North America*, 46(3), 341-50, vii.
doi:10.1016/j.cnur.2011.05.005

Patients using the Internet are inundated with abundant information on health care that may be correct and may be incorrect. It is becoming the role of clinicians to enable

patients to educate themselves by providing information about accurate and reliable Web sites, and to answer questions from literature that patients encounter. In addition, there is a myriad of technological advances to help patients and clinicians access, retrieve, and file information, and numerous communication tools to foster the patient-clinician dialog. This article provides an overview and some recommendations for clinicians to help patients better use information to achieve better outcomes.

Grisot, M., Van Der Velden, M., & Vassilakopoulou, P. (2011). Socio-technical challenges in designing a web-based communication platform. *Studies in Health Technology and Informatics*, 169, 68-72.

This paper takes a socio-technical perspective to analyze the ongoing practices of making an eHealth infrastructure, namely a web-based communication platform, which aims to improve healthcare delivery in Norway. The platform is planned to support interaction between patients and healthcare providers, patient access to personal health information, and dissemination of health knowledge to the public. The analysis is based on the 'scales of infrastructure' concept found in Information Systems research, which shows the complexity of the design, development and implementation process across three scales of activities for achieving durability: institutionalization, organizing work, and technology enactment. The case analysis brings the non-linearity of the ongoing practices to the foreground, enabling a more in-depth understanding of the relationship between technology design and infrastructural work.

Hardiker, N. R., & Grant, M. J. (2011). Factors that influence public engagement with eHealth: A literature review. *International Journal of Medical Informatics*, 80(1), 1-12.

doi:DOI: 10.1016/j.ijmedinf.2010.10.017

Purpose Public engagement with eHealth is generally viewed as beneficial. However, despite the potential benefits, public engagement with eHealth services remains variable. This article explores reasons for this variability through a review of published international literature. Methods A focused search, conducted in January 2009, of three bibliographic databases, MEDLINE, CINAHL and EMBASE, returned 2622 unique abstracts. Results Fifty articles met the inclusion criteria for the review. Four main types of eHealth service were identified: health information on the Internet; custom-made online health information; online support; and telehealth. Public engagement with these services appears to depend on a number of factors: characteristics of users; technological issues; characteristics of eHealth services; social aspects of use; and eHealth services in use. Conclusions Recommendations for policy makers, developers, users and health professionals, include: targeting efforts towards those underserved by eHealth; improving access; tailoring services to meet the needs of a broader range of users; exploiting opportunities for social computing; and clarifying of the role of health professionals in endorsement, promotion and facilitation.

Hogan, T. P., Wakefield, B., Nazi, K. M., Houston, T. K., & Weaver, F. M. (2011). Promoting access through complementary eHealth technologies: Recommendations for VA's Home Telehealth and personal health record programs. *Journal of General Internal Medicine, 26 Suppl 2*, 628-635. doi:10.1007/s11606-011-1765-y

BACKGROUND: Many healthcare organizations have embraced eHealth technologies in their efforts to promote patient-centered care, increase access to services, and improve outcomes. OBJECTIVE: Using the Department of Veterans Affairs (VA) as a case study,

this paper presents two specific eHealth technologies, the Care Coordination Home Telehealth (CCHT) Program and the My HealtheVet (MHV) personal health record (PHR) portal with integrated secure messaging, and 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. METHODS: Based on our experience and ongoing work with both programs, we offer a series of recommendations for pursuing and ultimately achieving this vision. CONCLUSION: VA's CCHT and MHV programs are examples of an expanding repertoire of eHealth applications available to patients and healthcare teams. 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.

Kahlor, L. (2010). PRISM: a planned risk information seeking model. *Health Communication*, 25(4), 345-356.

Recent attention on health-related information seeking has focused primarily on information seeking within specific health and health risk contexts. This study attempts to shift some of that focus to individual-level variables that may impact health risk information seeking across contexts. To locate these variables, the researcher posits an integrated model, the Planned Risk Information Seeking Model (PRISM). The model, which treats risk information seeking as a deliberate (planned) behavior, maps variables found in the Theory of Planned Behavior (TPB; Ajzen, 1991)

and the Risk Information Seeking and Processing Model (RISP; Griffin, Dunwoody, & Neuwirth, 1999), and posits linkages among those variables. This effort is further informed by Kahlor's (2007) Augmented RISP, the Theory of Motivated Information Management (Afifi & Weiner, 2004), the Comprehensive Model of Information Seeking (Johnson & Meischke, 1993), the Health Information Acquisition Model (Freimuth, Stein, & Kean, 1989), and the Extended Parallel Processing Model (Witte, 1998). The resulting integrated model accounted for 59% of the variance in health risk information-seeking intent and performed better than the TPB or the RISP alone.

Krist, A. H., Peele, E., Woolf, S. H., Rothemich, S. F., Loomis, J. F., Longo, D. R., & Kuzel, A. J. (2011). Designing a patient-centered personal health record to promote preventive care. *BMC Medical Informatics and Decision Making*, 11, 73. doi:10.1186/1472-6947-11-73

BACKGROUND: Evidence-based preventive services offer profound health benefits, yet Americans receive only half of indicated care. A variety of government and specialty society policy initiatives are promoting the adoption of information technologies to engage patients in their care, such as personal health records, but current systems may not utilize the technology's full potential. METHODS: Using a previously described model to make information technology more patient-centered, we developed an interactive preventive health record (IPHR) designed to more deeply engage patients in preventive care and health promotion. We recruited 14 primary care practices to promote the IPHR to all adult patients and sought practice and patient input in designing the IPHR to ensure its usability, salience, and generalizability. 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. RESULTS: The IPHR that emerged from this process generates tailored patient recommendations based on guidelines from the U.S. Preventive Services Task Force and other organizations. It extracts clinical data from the practices' electronic medical record and obtains health risk assessment information from patients. Clinical content is translated and explained in lay language. Recommendations review the benefits and uncertainties of services and possible actions for patients and clinicians. Embedded in recommendations are self management tools, risk calculators, decision aids, and community resources--selected to match patient's clinical circumstances. Within six months, practices had encouraged 14.4% of patients to use the IPHR (ranging from 1.5% to 28.3% across the 14 practices). Practices successfully incorporated the IPHR into workflow, using it to prepare patients for visits, augment health behavior counseling, explain test results, automatically issue patient reminders for overdue services, prompt clinicians about needed services, and formulate personalized prevention plans. CONCLUSIONS: The IPHR demonstrates that a patient-centered personal health record that interfaces with the electronic medical record 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. TRIAL REGISTRATION: Clinicaltrials.gov identifier: NCT00589173.

Krohn, R. (2007). The consumer-centric personal health record--it's time. *Journal of Healthcare Information Management : JHIM*, 21(1), 20-23.

Today's healthcare financing and delivery industries are requiring consumers to become more actively engaged in decisions related to their health, to personally manage their healthcare expenses, and to assume greater responsibility for the ongoing health of themselves and their loved ones. This article addresses various issues driving consumer engagement and how PHRs can support this.

Li, Y. C., Detmer, D. E., Shabbir, S. A., Nguyen, P. A., Jian, W. S., Mihalas, G. I., . . . Kimura, M. (2012). A global travelers' electronic health record template standard for personal health records. *Journal of the American Medical Informatics Association*, 19(1), 134-136. doi:10.1136/amiajnl-2011-000323

Tourism as well as international business travel creates health risks for individuals and populations both in host societies and home countries. One strategy to reduce health-related risks to travelers is to provide travelers and relevant caregivers timely, ongoing access to their own health information. Many websites offer health advice for travelers. For example, the WHO and US Department of State offer up-to-date health information about countries relevant to travel. However, little has been done to assure travelers that their medical information is available at the right place and time when the need might arise. Applications of Information and Communication Technology (ICT) utilizing mobile phones for health management are promising tools both for the delivery of healthcare services and the promotion of personal health. This paper describes the project developed by international informaticians under the umbrella of the International Medical Informatics Association. A template capable of becoming an international standard is proposed. This application is available free to anyone who is interested. Furthermore, its source code is made open.

Nazi, K. M., Hogan, T. P., Wagner, T. H., McInnes, D. K., Smith, B. M., Haggstrom, D., . . .

Weaver, F. M. (2010). Embracing a health services research perspective on personal health records: lessons learned from the VA My HealtheVet system. *Journal of General Internal Medicine, 25 Suppl 1*, 62-67. doi:10.1007/s11606-009-1114-6

BACKGROUND: Personal health records (PHRs) are designed to help people manage information about their health. Over the past decade, there has been a proliferation of PHRs, but research regarding their effects on clinical, behavioral, and financial outcomes remains limited. The potential for PHRs to facilitate patient-centered care and health system transformation underscores the importance of embracing a broader perspective on PHR research. OBJECTIVE: Drawing from the experiences of VA staff to evaluate the My HealtheVet (MHV) PHR, this article advocates for a health services research perspective on the study of PHR systems. METHODS: We 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. CONCLUSION: These lessons are applicable to other PHR systems and the conduct of PHR research across different organizational contexts.

Or, C. K., Karsh, B. T., Severtson, D. J., Burke, L. J., Brown, R. L., & Brennan, P. F. (2011).

Factors affecting home care patients' acceptance of a web-based interactive self-management technology. *Journal of the American Medical Informatics Association, 18(1)*, 51-59. doi:10.1136/jamia.2010.007336

OBJECTIVE: With the advent of personal health records and other patient-focused health technologies, there is a growing need to better understand factors that

contribute to acceptance and use of such innovations. In this study, we employed the Unified Theory of Acceptance and Use of Technology as the basis for determining what predicts patients' acceptance (measured by behavioral intention) and perceived effective use of a web-based, interactive self-management innovation among home care patients. DESIGN: Cross-sectional secondary analysis of data from a randomized field study evaluating a technology-assisted home care nursing practice with adults with chronic cardiac disease. MEASUREMENT AND ANALYSIS: A questionnaire was designed based on validated measurement scales from prior research and was completed by 101 participants for measuring the acceptance constructs as part of the parent study protocol. Latent variable modeling with item parceling guided assessment of patients' acceptance. RESULTS: Perceived usefulness accounted for 53.9% of the variability in behavioral intention, the measure of acceptance. Together, perceived usefulness, health care knowledge, and behavioral intention accounted for 68.5% of the variance in perceived effective use. Perceived ease of use and subjective norm indirectly influenced behavioral intention, through perceived usefulness. Perceived ease of use and subjective norm explained 48% of the total variance in perceived usefulness. CONCLUSION: The study demonstrates that perceived usefulness, perceived ease of use, subjective norm, and healthcare knowledge together predict most of the variance in patients' acceptance and self-reported use of the web-based self-management technology.

Poon, E. G., Wald, J., Schnipper, J. L., Grant, R., Gandhi, T. K., Volk, L. A., . . . Middleton, B. (2007). Empowering patients to improve the quality of their care: design and implementation of a shared health maintenance module in a US integrated healthcare

delivery network. *Studies in Health Technology and Informatics*, 129(Pt 2), 1002-1006.

We describe a health maintenance module within a personal health record designed to improve the quality of routine preventive care for patients in a large integrated healthcare delivery network. This module allows patients and their providers to share an online medical record and decision support tools. Our preliminary results indicate that this approach is well-accepted by patients and their providers and has significant potential to facilitate patient-provider communication and improve the quality of routine health maintenance care. Further research will determine the long term impact and sustainability of this approach.

Quantin, C., Benzenine, E., Auverlot, B., Jaquet-Chiffelle, D. O., Coatrieux, G., & Allaert, F. A. (2011). Empowerment of patients over their personal health record implies sharing responsibility with the physician. *Studies in Health Technology and Informatics*, 165, 68-73.

Through this article, we point out the unavoidable empowerment of patients with regard to their personal health record and propose the mixed management of patients' medical records. This mixed management implies sharing responsibilities between the patient and the Medical Practitioner (MP) by making patients responsible for the validation of their administrative information, and MPs responsible for the validation of their patients' medical information. We propose a solution to gather and update patients' administrative and medical data in order to reconstitute patients' medical histories accurately. This method is based on two processes. The aim of the first process is to provide patients administrative data, in order to know where and when they received care (name of the health structure or health practitioner, type of care:

outpatient or inpatient). The aim of the second process is to provide patients' medical information and to validate it under the responsibility of the MP with the help of patients if needed. During these two processes, the patients' privacy will be ensured through cryptographic hash functions like the Secure Hash Algorithm, which allows the pseudonymization of patients' identities. The Medical Record Search Engine we propose will be able to retrieve and to provide upon a request formulated by the MP all the available information concerning a patient who has received care in different health structures without divulging the patient's true identity. Associated with strong traceability of all access, modifications or deletions, our method can lead to improved efficiency of personal medical record management while reinforcing the empowerment of patients over their medical records.

Randeree, E. (2009). Exploring technology impacts of Healthcare 2.0 initiatives.

Telemedicine Journal and e-Health, 15(3), 255-260. doi:10.1089/tmj.2008.0093

As Internet access proliferates and technology becomes more accessible, the number of people online has been increasing. Web 2.0 and the social computing phenomena (such as Facebook, Friendster, Flickr, YouTube, Blogger, and MySpace) are creating a new reality on the Web: Users are changing from consumers of Web-available information and resources to generators of information and content. Moving beyond telehealth and Web sites, the push toward Personal Health Records has emerged as a new option for patients to take control of their medical data and to become active participants in the push toward widespread digitized healthcare. There is minimal research on the impact of Web 2.0 in healthcare. This paper reviews the changing

patient-physician relationship in the Healthcare 2.0 environment, explores the technological challenges, and highlights areas for research.

Saranummi, N. (2009). In the Spotlight: Health Information Systems - PHR and Value Based Healthcare. *IEEE Reviews in Biomedical Engineering*, 2, 15-17.

doi:10.1109/RBME.2009.2034699

The author discusses recent progress in personal health records (PHR). The column is structured as follows: first, a look at what is driving health reform concluding with the need to make "value" the first priority. The role of citizens and patients in the value drive is then discussed. They must be empowered to act as co-producers in cooperation with healthcare professionals. Lastly, the role of the PHR and services based on the PHR will be elaborated.

Scherger, J. E. (2009). Future vision: is family medicine ready for patient-directed care? *Family Medicine*, 41(4), 285-288.

A growing number of Americans will soon have a Web-based personal medical home with connectedness to their chosen providers of care. The personal health record will become integrated with the electronic health record. Like other services on the Internet, patients will be able to direct much of their health care using clinical guidelines, such as prevention, chronic illness care, behavior change, and arrangement for minor acute care. Physician control and autonomy will give way to greater patient control over their care, a major culture change in medicine away from paternalism. While the personal family physician will continue as a primary caregiver, there will be a shift toward greater patient involvement in the coordination of care. Family medicine

educators should begin now to educate medical students and residents for this new model of care.

Sensmeier, J. E. (2010). The journey toward a personal health record. *Nursing Management*, 41(2), 47-50. doi:10.1097/01.NUMA.0000368568.05221.5a

The purpose of this article is to define what a PHR is and describe the benefits of a PHR. It includes considerations for selection and implementation of a PHR.

Siek, K. A., Ross, S. E., Khan, D. U., Haverhals, L. M., Cali, S. R., & Meyers, J. (2010). Colorado Care Tablet: The design of an interoperable Personal Health Application to help older adults with multimorbidity manage their medications. *Journal of Biomedical Informatics*, 43(5 Suppl), S22-6.

Medication errors are common and cause serious health issues during care transitions, particularly for older adults with multiple chronic conditions. In this paper, we discuss the design and evaluation of the Colorado Care Tablet, a Personal Health Application (PHA) that helps older adults and their lay caregivers manage their medication regimes during care transitions. We created a PHA that older adults with limited computing experience could easily use by designing an application based on their real world artifacts and workflows. Copyright Copyright 2010 Elsevier Inc. All rights reserved.

Tang, P. C., & Lansky, D. (2005). The missing link: bridging the patient-provider health information gap. *Health Affairs (Project Hope)*, 24(5), 1290-1295.

doi:10.1377/hlthaff.24.5.1290

Widespread adoption of information technology is now regarded as a pathway to

improving health care and achieving the Institute of Medicine's highly regarded six aims for redesigning care. Achieving these aims requires fresh approaches to health system design, including continuous healing relationships between physicians and patients and provision of tools to help patients be more active participants in their own care. Personal health records (PHRs) might allow patients and providers to develop new ways of collaborating and provide the basis for broader transformation of the health care system. Federal policies can be key catalysts in accelerating PHR development and adoption.

Tulu, B., & Horan, T. A. (2009). The electronic disability record: Purpose, parameters, and model use case. *Journal of the American Medical Informatics Association*, 16(1), 7-13. doi:10.1197/jamia.M2405

The active engagement of consumers is an important factor in achieving widespread success of health information systems. The disability community represents a major segment of the healthcare arena, with more than 50 million Americans experiencing some form of disability. In keeping with the "consumer-driven" approach to e-health systems, this paper considers the distinctive aspects of electronic and personal health record use by this segment of society. Drawing upon the information shared during two national policy forums on this topic, the authors present the concept of Electronic Disability Records (EDR). The authors outline the purpose and parameters of such records, with specific attention to its ability to organize health and financial data in a manner that can be used to expedite the disability determination process. In doing so, the authors discuss its interaction with Electronic Health Records (EHR) and Personal Health Records (PHR). The authors then draw upon these general parameters to

outline a model use case for disability determination and discuss related implications for disability health management. The paper further reports on the subsequent considerations of these and related deliberations by the American Health Information Community (AHIC).

Weitzman, E. R., Kaci, L., & Mandl, K. D. (2009). Acceptability of a personally controlled health record in a community-based setting: Implications for policy and design. *Journal of Medical Internet Research*, 11(2), e14. doi:10.2196/jmir.1187

BACKGROUND: Consumer-centered health information systems that address problems related to fragmented health records and disengaged and disempowered patients are needed, as are information systems that support public health monitoring and research. Personally controlled health records (PCHRs) represent one response to these needs. PCHRs are a special class of personal health records (PHRs) distinguished by the extent to which users control record access and contents. Recently launched PCHR platforms include Google Health, Microsoft's HealthVault, and the Dossia platform, based on Indivo. OBJECTIVE: To understand the acceptability, early impacts, policy, and design requirements of PCHRs in a community-based setting. METHODS: Observational and narrative data relating to acceptability, adoption, and use of a personally controlled health record were collected and analyzed within a formative evaluation of a PCHR demonstration. Subjects were affiliates of a managed care organization run by an urban university in the northeastern United States. Data were collected using focus groups, semi-structured individual interviews, and content review of email communications. Subjects included: n = 20 administrators, clinicians, and institutional stakeholders who participated in pre-deployment group or individual

interviews; n = 52 community members who participated in usability testing and/or pre-deployment piloting; and n = 250 subjects who participated in the full demonstration of which n = 81 initiated email communications to troubleshoot problems or provide feedback. All data were formatted as narrative text and coded thematically by two independent analysts using a shared rubric of a priori defined major codes. Sub-themes were identified by analysts using an iterative inductive process. Themes were reviewed within and across research activities (ie, focus group, usability testing, email content review) and triangulated to identify patterns. RESULTS: Low levels of familiarity with PCHRs were found as were high expectations for capabilities of nascent systems. Perceived value for PCHRs was highest around abilities to co-locate, view, update, and share health information with providers. Expectations were lowest for opportunities to participate in research. Early adopters perceived that PCHR benefits outweighed perceived risks, including those related to inadvertent or intentional information disclosure. Barriers and facilitators at institutional, interpersonal, and individual levels were identified. Endorsement of a dynamic platform model PCHR was evidenced by preferences for embedded searching, linking, and messaging capabilities in PCHRs; by high expectations for within-system tailored communications; and by expectation of linkages between self-report and clinical data. CONCLUSIONS: Low levels of awareness/preparedness and high expectations for PCHRs exist as a potentially problematic pairing. Educational and technical assistance for lay users and providers are critical to meet challenges related to: access to PCHRs, especially among older cohorts; workflow demands and resistance to change among providers; inadequate health and technology literacy; clarification of boundaries and

responsibility for ensuring accuracy and integrity of health information across distributed data systems; and understanding confidentiality and privacy risks.

Continued demonstration and evaluation of PCHRs is essential to advancing their use.

Weitzman, E. R., Kaci, L., & Mandl, K. D. (2010). Sharing medical data for health research:

The early personal health record experience. *Journal of Medical Internet Research*, 12(2), e14. doi:10.2196/jmir.1356

BACKGROUND: Engaging consumers in sharing information from personally controlled health records (PCHRs) for health research may promote goals of improving care and advancing public health consistent with the federal Health Information Technology for Economic and Clinical Health (HITECH) Act. Understanding consumer willingness to share data is critical to advancing this model. OBJECTIVE: The objective was to characterize consumer willingness to share PCHR data for health research and the conditions and contexts bearing on willingness to share. METHODS: A mixed method approach integrating survey and narrative data was used. Survey data were collected about attitudes toward sharing PCHR information for health research from early adopters (n = 151) of a live PCHR populated with medical records and self-reported behavioral and social data. Data were analyzed using descriptive statistics and logistic regression to characterize willingness, conditions for sharing, and variations by sociodemographic factors. Narrative data were collected through semistructured focus group and one-on-one interviews with a separate sample of community members (n = 30) following exposure to PCHR demonstrations. Two independent analysts coded narrative data for major and minor themes using a shared rubric of a priori defined codes and an iterative inductive process. Findings were triangulated with survey

results to identify patterns. RESULTS: Of PHCR users, 138 out of 151 (91%) were willing to share medical information for health research with 89 (59%) favoring an opt-in sharing model. Willingness to share was conditioned by anonymity, research use, engagement with a trusted intermediary, transparency around PCHR access and use, and payment. Consumer-determined restrictions on content and timing of sharing may be prerequisites to sharing. 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 (unadjusted odds ratio [OR] = 2.89, 95% confidence interval [CI] 1.10 - 7.62, $P = .03$). Participants over age 50 were less likely than younger participants to report that payment would increase willingness to share (unadjusted OR = 0.94, 95% CI 0.91 - 0.96, $P < .001$). Students were more likely than nonstudents to report that payment would increase their willingness to share (unadjusted OR 9.62, 95% CI 3.44 - 26.87, $P < .001$). Experiencing a public health emergency may increase willingness to share especially among persons over 50 (unadjusted OR 1.03, 95% CI 1.01 - 1.05, $P = .02$); however, students were less likely than non-students to report this attitude (unadjusted OR 0.13, 95% CI 0.05 - 0.36, $P < .001$). 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 (unadjusted OR 0.61, 95% CI 0.38 - 0.97, $P = .04$). CONCLUSIONS: 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.

Exchange/Interoperability – Annotated Bibliography

Anoshiravani, A., Gaskin, G., Kopetsky, E., Sandborg, C., & Longhurst, C. A. (2011).

Implementing an interoperable personal health record in pediatrics: Lessons learned at an academic children's hospital. *Journal of Participatory Medicine*, 3, e30.

This paper describes the development of an innovative health information technology creating a bidirectional link between the electronic medical record (EMR) of an academic children's hospital and a commercially available, interoperable personal health record (PHR). The goal of the PHR project has been to empower pediatric patients and their families to play a more active role in understanding, accessing, maintaining, and sharing their personal health information to ultimately improve health outcomes. The most notable challenges proved more operational and cultural than technological. Our experience demonstrates that an interoperable PHR is technically and culturally achievable at a pediatric academic medical center.

Recognizing the complex social, cultural, and organizational contexts of these systems is important for overcoming barriers to a successful implementation.

Baumlin, K. M., Genes, N., Landman, A., Shapiro, J. S., Taylor, T., Janiak, B., & 2010 Academic emergency medicine consensus conference Beyond regionalization: Intergrated networks of emergency care. (2010). Electronic collaboration: Using technology to solve old problems of quality care. *Academic Emergency Medicine*, 17(12), 1312-1321. doi:10.1111/j.1553-2712.2010.00933.x; 10.1111/j.1553-2712.2010.00933.x

The participants of the Electronic Collaboration working group of the 2010 Academic Emergency Medicine consensus conference developed recommendations and research

questions for improving regional quality of care through the use of electronic collaboration. A writing group devised a working draft prior to the meeting and presented this to the breakout session at the consensus conference for input and approval. The recommendations include: 1) patient health information should be available electronically across the entire health care delivery system from the 9-1-1 call to the emergency department (ED) visit through hospitalization and outpatient care, 2) relevant patient health information should be shared electronically across the entire health care delivery system, 3) Web-based collaborative technologies should be employed to facilitate patient transfer and timely access to specialists, 4) personal health record adoption should be considered as a way to improve patient health, and 5) any comprehensive reform of regionalization in emergency care must include telemedicine. The workgroup emphasized the need for funding increases so that research in this new and exciting area can expand.

Benhamou, P. Y. (2011). Improving diabetes management with electronic health records and patients' health records. *Diabetes & Metabolism*, 37(Suppl 4), S53-6.

doi:10.1016/S1262-3636(11)70966-1

The lack of patient engagement and clinical inertia both contribute to suboptimal diabetes care. However, both obstacles are amenable to informatics- and Internet-based interventions. The use of electronic medical records (EMRs) is now established as being useful for improving diabetes care. Intelligent records that integrate computerized decision-support systems are now able to recommend care protocols tailored to risk levels. Web-based personal health record (PHR) systems, shared with healthcare providers, could also provide added value by promoting self-management

of the behaviours related to diabetes. These Web-based programmes include patients' access to EMRs, uploading of glucose monitoring results, a glucose diary, secure e-mail with providers, manual or automated feedback on blood glucose readings and other risk factors, an educational website, and an online diary for entering personal information on exercise, diet and medication. The integration of Web-based patients' systems into the EMR used by physicians is the next frontier. In addition, the input from "smartphones" that are able to provide real-time support to patients could contribute to the reorganization of diabetes care. Convincing data on HbA(1c) improvements with such systems are available for type 2 diabetes, but are still equivocal for type 1 diabetes. Obstacles include patients' compliance with the technology, their ergonomic design and the need to reimburse providers for their care. Designing appropriate electronic tools and tailoring them to the conditions in France merits our attention.

Berry, J. G., Goldmann, D. A., Mandl, K. D., Putney, H., Helm, D., O'Brien, J., . . . Weinick, R. M. (2011). Health information management and perceptions of the quality of care for children with tracheotomy: A qualitative study. *BMC Health Services Research*, *11*, 117. doi:10.1186/1472-6963-11-117

BACKGROUND: Children with tracheotomy receive health care from an array of providers within various hospital and community health system sectors. Previous studies have highlighted substandard health information exchange between families and these sectors. The aim of this study was to investigate the perceptions and experiences of parents and providers with regard to health information management, care plan development and coordination for children with tracheotomy, and strategies

to improve health information management for these children. **METHODS:** Individual and group interviews were performed with eight parents and fifteen healthcare (primary and specialty care, nursing, therapist, equipment) providers of children with tracheotomy. The primary tracheotomy-associated diagnoses for the children were neuromuscular impairment (n = 3), airway anomaly (n = 2) and chronic lung disease (n = 3). Two independent reviewers conducted deep reading and line-by-line coding of all transcribed interviews to discover themes associated with the objectives. **RESULTS:** Children with tracheotomy in this study had healthcare providers with poorly defined roles and responsibilities who did not actively communicate with one another. Providers were often unsure where to find documentation relating to a child's tracheotomy equipment settings and home nursing orders, and perceived that these situations contributed to medical errors and delayed equipment needs. Parents created a home record that was shared with multiple providers to track the care that their children received but many considered this a burden better suited to providers. Providers benefited from the parent records, but questioned their accuracy regarding critical tracheotomy care plan information such as ventilator settings. Parents and providers endorsed potential improvement in this environment such as a comprehensive internet-based health record that could be shared among parents and providers, and between various clinical sites. **CONCLUSIONS:** Participants described disorganized tracheotomy care and health information mismanagement that could help guide future investigations into the impact of improved health information systems for children with tracheotomy. Strategies with the potential to improve tracheotomy care delivery could include defined roles and responsibilities for

tracheotomy providers, and improved organization and parent support for maintenance of home-based tracheotomy records with web-based software applications, personal health record platforms and health record data authentication techniques.

Do, N. V., Barnhill, R., Heermann-Do, K. A., Salzman, K. L., & Gimbel, R. W. (2011). The military health system's personal health record pilot with Microsoft HealthVault and Google Health. *Journal of the American Medical Informatics Association, 18*(2), 118-124. doi:10.1136/jamia.2010.004671

OBJECTIVE: To design, build, implement, and evaluate a personal health record (PHR), tethered to the Military Health System, that leverages Microsoft(R) HealthVault and Google(R) Health infrastructure based on user preference. **MATERIALS AND METHODS:** A pilot project was conducted in 2008-2009 at Madigan Army Medical Center in Tacoma, Washington. Our PHR was architected to a flexible platform that incorporated standards-based models of Continuity of Document and Continuity of Care Record to map Department of Defense-sourced health data, via a secure Veterans Administration data broker, to Microsoft(R) HealthVault and Google(R) Health based on user preference. The project design and implementation were guided by provider and patient advisory panels with formal user evaluation. **RESULTS:** The pilot project included 250 beneficiary users. Approximately 73.2% of users were < 65 years of age, and 38.4% were female. Of the users, 169 (67.6%) selected Microsoft(R) HealthVault, and 81 (32.4%) selected Google(R) Health as their PHR of preference. Sample evaluation of users reflected 100% (n = 60) satisfied with convenience of record access and 91.7% (n = 55) satisfied with overall functionality of PHR. **DISCUSSION:** 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. CONCLUSION: Currently PHRs are being viewed as empowering tools for patient activation. Design and implementation issues (eg, technical, organizational, information security) are substantial and must be thoughtfully approached. Adopting standards into design can enhance the national goal of portability and interoperability.

Jian, W. S., Wen, H. C., Scholl, J., Shabbir, S. A., Lee, P., Hsu, C. Y., & Li, Y. C. (2011). The Taiwanese method for providing patients data from multiple hospital EHR systems. *Journal of Biomedical Informatics*, 44(2), 326-332. doi:10.1016/j.jbi.2010.11.004

Personal Health Record (PHR) systems are growing in popularity and are receiving increased attention from the Biomedical Informatics research community. Information Collection is one PHR research topic and includes system functionality that helps patients retrieve their data from external sources. One of the most potentially useful external sources of information is the data stored in patients' EHRs at medical institutions. PHR systems that support Information Collection from EHR systems are thus interesting to investigate. In this paper we present PHR system that allows patients to receive data from 10 participating hospitals in Taiwan via a USB flash memory device. The overall design goals and architecture for the system are presented. Based on our experiences in designing and implementing the system we propose a three step method for accomplishing Information Collection from EHR systems at medical institutions for similar PHR systems in the future.

Marshall, P. (2009). Keeping tabs. How personal health records are changing the face of healthcare. *Marketing Health Services*, 29(4), 20-25.

The authors provide a definition for PHRs, use in health care, standards, objectives to achieve, and requirements for connecting care. The benefits of using a PHR are described. The authors also describe how to market the use of a PHR.

Pringle, S., & Lippitt, A. (2009). Interoperability of electronic health records and personal health records: Key interoperability issues associated with information exchange. *Journal of Healthcare Information Management*, 23(3), 31-37.

As patients receive medical care, their clinical history may be tracked and recorded by multiple electronic systems developed by independent vendors. Medical providers might use electronic health record (EHR) software tailored to the needs of trained medical personnel, whereas patients may interact with personal health records (PHR). The purpose of this essay is to identify the key interoperability issues associated with the information exchange between these two types of systems and offer an approach for enhancing interoperability. This article is part of a series of unpublished essays titled A Community View on How Personal Health Records Can Improve Patient Care and Outcomes in Many Healthcare Settings, a collaborative project of Northern Illinois Physicians For Connectivity and the Coalition for Quality and Patient Safety of Chicagoland. For further information on how you can obtain copies of the complete work, contact the principle Dr. Stasia Kahn at Stash5@sbcglobal.net.

Quantin, C., Benzenine, E., Auverlot, B., Jaquet-Chiffelle, D. O., Coatrieux, G., & Allaert, F. A. (2011). Empowerment of patients over their personal health record implies sharing

responsibility with the physician. *Studies in Health Technology and Informatics*, 165, 68-73.

Through this article, we point out the unavoidable empowerment of patients with regard to their personal health record and propose the mixed management of patients' medical records. This mixed management implies sharing responsibilities between the patient and the Medical Practitioner (MP) by making patients responsible for the validation of their administrative information, and MPs responsible for the validation of their patients' medical information. We propose a solution to gather and update patients' administrative and medical data in order to reconstitute patients' medical histories accurately. This method is based on two processes. The aim of the first process is to provide patients administrative data, in order to know where and when they received care (name of the health structure or health practitioner, type of care: outpatient or inpatient). The aim of the second process is to provide patients' medical information and to validate it under the responsibility of the MP with the help of patients if needed. During these two processes, the patients' privacy will be ensured through cryptographic hash functions like the Secure Hash Algorithm, which allows the pseudonymization of patients' identities. The Medical Record Search Engine we propose will be able to retrieve and to provide upon a request formulated by the MP all the available information concerning a patient who has received care in different health structures without divulging the patient's true identity. Associated with strong traceability of all access, modifications or deletions, our method can lead to improved efficiency of personal medical record management while reinforcing the empowerment of patients over their medical records.

Sensmeier, J., & Casey Halley, E. (2009). Connecting humans and health through health information exchange. *Studies in Health Technology and Informatics*, 146, 756-757.

To address healthcare quality, efficiency and safety, a national health information technology (IT) initiative was announced by the President of the United States in 2004 to make Electronic Health Records (EHR) available to most Americans within 10 years. The National Health IT Agenda has advanced with recognition of interoperability standards for Personal Health Records (PHR) and Population Health information exchange. This session will illustrate the national processes, timeline, stakeholders and benefits of adoption of interoperability standards to enable health information exchange.

Turvey, C. L., Zulman, D. M., Nazi, K. M., Wakefield, B. J., Woods, S. S., Hogan, T. P., . . .

McInnes, K. (2012). Transfer of information from personal health records: A survey of veterans using My HealtheVet. *Telemedicine Journal and e-Health*, , 14.

doi:10.1089/tmj.2011.0109

Abstract Objective: Personal health records provide patients with ownership of their health information and allow them to share information with multiple healthcare providers. However, the usefulness of these records relies on patients understanding and using their records appropriately. My HealtheVet is a Web-based patient portal containing a personal health record administered by the Veterans Health Administration. The goal of this study was to explore veterans' interest and use of My HealtheVet to transfer and share information as well as to identify opportunities to increase veteran use of the My HealtheVet functions. Materials and Methods: Two waves of data were collected in 2010 through an American Customer Satisfaction

Index Web-based survey. A random sample of veterans using My HealtheVet was invited to participate in the survey conducted on the My HealtheVet portal through a Web-based pop-up browser window. Results: Wave One results (n=25,898) found that 41% of veterans reported printing information, 21% reported saving information electronically, and only 4% ever sent information from My HealtheVet to another person. In Wave Two (n=18,471), 30% reported self-entering medication information, with 18% sharing this information with their Veterans Affairs (VA) provider and 9.6% sharing with their non-VA provider. Conclusion: Although veterans are transferring important medical information from their personal health records, increased education and awareness are needed to increase use. Personal health records 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.

Zulman, D. M., Nazi, K. M., Turvey, C. L., Wagner, T. H., Woods, S. S., & An, L. C. (2011).

Patient interest in sharing personal health record information: A web-based survey. *Annals of Internal Medicine*, 155(12), 805-810. doi:10.1059/0003-4819-155-12-201112200-00002

BACKGROUND: Electronic personal health record (PHR) systems are proliferating but largely have not realized their potential for enhancing communication among patients and their network of care providers. OBJECTIVE: To explore preferences about sharing electronic health information among users of the U.S. Department of Veterans Affairs (VA) PHR system, My HealtheVet. DESIGN: Web-based survey of a convenience sample. SETTING: My HealtheVet Web site from 7 July through 4 October 2010.

PARTICIPANTS: 18 471 users of My HealtheVet. **MEASUREMENTS:** Interest in shared PHR access and preferences about who would receive access, the information that would be shared, and the activities that users would delegate. **RESULTS:** Survey respondents were predominantly men (92%) and aged 50 to 64 years (51%) or 65 years or older (39%); approximately 39% reported poor or fair health status. Almost 4 of 5 respondents (79%) were interested in sharing access to their PHR with someone outside of their health system (62% with a spouse or partner, 23% with a child, 15% with another family member, and 25% with a non-VA health care provider). Among those who selected a family member other than a spouse or partner, 47% lived apart from the specified person. Preferences about degree of access varied on the basis of the type of information being shared, the type of activity being performed, and the respondent's relationship with the selected person. **LIMITATIONS:** The survey completion rate was 40.8%. Results might not be generalizable to all My HealtheVet users. **CONCLUSION:** In a large survey of PHR users in the VA system, most respondents were interested in sharing access to their electronic health information with caregivers and non-VA providers. Existing and evolving PHR systems should explore secure mechanisms for shared PHR access to improve information exchange among patients and the multiple persons involved in their health care. **PRIMARY FUNDING SOURCE:** Veterans Health Administration and The Robert Wood Johnson Foundation Clinical Scholars Program.

Features – Annotated Bibliography

Ahmadi, M., Jeddi, F. R., Gohari, M. R., & Sadoughi, F. (2012). A review of the personal health records in selected countries and Iran. *Journal of Medical Systems, 36*(2), 371-82.

doi:10.1007/s10916-010-9482-3

Personal Health Record (PHR) enables patients to access their health information and improves care quality by supporting self-care. The purpose of this study is to provide a comparative analysis of the concept of PHRs in selected countries and Iran in order to investigate the gaps between Iran and more advanced countries in terms of PHRs. The study was carried out in 2008-2009 using a descriptive-comparative method in Australia, the United States, England and Iran. Data was gathered from articles, books, journals and reputed websites in English and Persian published between 1995 and September 2009. After collecting the data, both advantages and disadvantages of each of concepts were analyzed. In the three countries considered in the present study the concepts of PHR, extracted from the literature, are that; a) patient/person be recognized as the owner of PHR; b) information be disclosed only to those authorized by the patient; c) and that PHR is created upon request and consent of the individual involved. Before PHRs can be profitably used in the health administration of a (developing) country, the necessary knowledge, infrastructures, and rules need to be developed.

Allaert, F. A., & Quantin, C. (2010). Patients' empowerment of their personal health record requires strong traceability to guarantee patients health care security. *Studies in Health Technology and Informatics, 155*, 43-47.

Giving patients power over their personal health record is an unavoidable evolution in all industrialized countries which will reflect their active participation in the management of their own health. This would lead to patients sharing management with health professionals, which would need traceability of the data provider to maintain trust and transparency. The systematic use of electronic signatures by medical practitioners will be essential to provide sufficient guarantees and to clearly determine who has added what in the PEHR.

Bates, D. W., & Bitton, A. (2010). The future of health information technology in the patient-centered medical home. *Health Affairs (Project Hope)*, 29(4), 614-621.

doi:10.1377/hlthaff.2010.0007

Most electronic health records today need further development of features that patient-centered medical homes require to improve their efficiency, quality, and safety. We propose a road map of the domains that need to be addressed to achieve these results. We believe that the development of electronic health records will be critical in seven major areas: telehealth, measurement of quality and efficiency, care transitions, personal health records, and, most important, registries, team care, and clinical decision support for chronic diseases. To encourage this development, policy makers should include medical homes in emerging electronic health record regulations. Additionally, more research is needed to learn how these records can enhance team care.

Benhamou, P. Y. (2011). Improving diabetes management with electronic health records and patients' health records. *Diabetes & Metabolism*, 37(Suppl 4), S53-6.

doi:10.1016/S1262-3636(11)70966-1

The lack of patient engagement and clinical inertia both contribute to suboptimal diabetes care. However, both obstacles are amenable to informatics- and Internet-based interventions. The use of electronic medical records (EMRs) is now established as being useful for improving diabetes care. Intelligent records that integrate computerized decision-support systems are now able to recommend care protocols tailored to risk levels. Web-based personal health record (PHR) systems, shared with healthcare providers, could also provide added value by promoting self-management of the behaviours related to diabetes. These Web-based programmes include patients' access to EMRs, uploading of glucose monitoring results, a glucose diary, secure e-mail with providers, manual or automated feedback on blood glucose readings and other risk factors, an educational website, and an online diary for entering personal information on exercise, diet and medication. The integration of Web-based patients' systems into the EMR used by physicians is the next frontier. In addition, the input from "smartphones" that are able to provide real-time support to patients could contribute to the reorganization of diabetes care. Convincing data on HbA(1c) improvements with such systems are available for type 2 diabetes, but are still equivocal for type 1 diabetes. Obstacles include patients' compliance with the technology, their ergonomic design and the need to reimburse providers for their care. Designing appropriate electronic tools and tailoring them to the conditions in France merits our attention.

Bodily, N. J., Carlston, D. A., & Rocha, R. A. (2007). Personal health records: key features within existing applications. *AMIA Annual Symposium Proceedings, 2007*, 875.

Personal Health Records (PHRs) have been developed as client-based and Internet-based applications. While there is no predominant industry standard or product, most applications have several key features in common. By researching several PHR applications we have isolated five important feature groups that are regularly implemented by existing products. While a majority of PHRs include these key features, the usability and accessibility of each varies from application to application.

Burrington-Brown, J., Fishel, J., Fox, L., Friedman, B., Giannangelo, K., Jacobs, E., . . . AHIMA e-HIM Personal Health Record Work Group. (2005). Defining the personal health record. AHIMA releases definition, attributes of consumer health record. *Journal of AHIMA*, 76(6), 24-25.

This paper provides definitions for PHR and then discusses the role an HIM professional might perform in order to increase PHR use in consumers. AHIMA definition from 2006.

Collins, S. A., Vawdrey, D. K., Kukafka, R., & Kuperman, G. J. (2011). Policies for patient access to clinical data via PHRs: Current state and recommendations. *Journal of the American Medical Informatics Association*, 18 Suppl 1(Suppl 1), i2-7.

doi:10.1136/amiajnl-2011-000400

OBJECTIVE: Healthcare delivery organizations are increasingly using online personal health records (PHRs) to provide patients with direct access to their clinical information; however, there may be a lack of consistency in the data made available. We aimed to understand the general use and functionality of PHRs and the organizational policies and decision-making structures for making data available to

patients. MATERIALS AND METHODS: A cross-sectional survey was administered by telephone structured interview to 21 organizations to determine the types of data made available to patients through PHRs and the presence of explicit governance for PHR data release. Organizations were identified based on a review of the literature, PHR experts, and snowball sampling. Organizations that did not provide patients with electronic access to their data via a PHR were excluded. RESULTS: Interviews were conducted with 17 organizations for a response rate of 81%. Half of the organizations had explicit governance in the form of a written policy that outlined the data types made available to patients. Overall, 88% of the organizations used a committee structure for the decision-making process and included senior management and information services. All organizations sought input from clinicians. Discussion There was considerable variability in the types of clinical data and the time frame for releasing these data to patients. Variability in data release policies may have implications for PHR use and adoption. CONCLUSIONS: Future policy activities, such as requirement specification for the latter stages of Meaningful Use, should be leveraged as an opportunity to encourage standardization of functionality and broad deployment of PHRs.

Council on Clinical Information Technology. (2011). Health information technology and the medical home. *Pediatrics*, 127(5), 978-982. doi:10.1542/peds.2011-0454

The American Academy of Pediatrics (AAP) supports development and universal implementation of a comprehensive electronic infrastructure to support pediatric information functions of the medical home. These functions include (1) timely and continuous management and tracking of health data and services over a patient's

lifetime for all providers, patients, families, and guardians, (2) comprehensive organization and secure transfer of health data during patient-care transitions between providers, institutions, and practices, (3) establishment and maintenance of central coordination of a patient's health information among multiple repositories (including personal health records and information exchanges), (4) translation of evidence into actionable clinical decision support, and (5) reuse of archived clinical data for continuous quality improvement. The AAP supports universal, secure, and vendor-neutral portability of health information for all patients contained within the medical home across all care settings (ambulatory practices, inpatient settings, emergency departments, pharmacies, consultants, support service providers, and therapists) for multiple purposes including direct care, personal health records, public health, and registries. The AAP also supports financial incentives that promote the development of information tools that meet the needs of pediatric workflows and that appropriately recognize the added value of medical homes to pediatric care.

Curtis, J., Cheng, S., Rose, K., & Tsai, O. (2011). Promoting adoption, usability, and research for personal health records in Canada: the MyChart experience. *Healthcare Management, 24*(3), 149-154.

Sunnybrook's MyChart Personal Health Record (PHR) represents a direct extension of the hospital's electronic health record and an innovative form of healthcare record that promises to change the way patients and providers access and manage the information required to participate in their care. Early attempts at the development of PHR features have evolved into a set of emergent best practices that should directly inform the ongoing development of the MyChart platform and should be complemented with a

research agenda that supports evidence-based analysis and design considerations affecting clinical efficacy, administrative efficiency, and value generation for all PHR stakeholders.

Haggstrom, D. A., Saleem, J. J., Russ, A. L., Jones, J., Russell, S. A., & Chumbler, N. R. (2011).

Lessons learned from usability testing of the VA's personal health record. *Journal of the American Medical Informatics Association*, 18 (Suppl 1), i13-7. doi:10.1136/amiajnl-2010-000082

In order to create user-centered design information to guide the development of personal health records (PHRs), 24 patients participated in usability assessments of VA's MyHealtheVet program. 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. Twenty-five percent of users successfully completed registration. Individuals preferred prescription numbers over names, sometimes due to privacy concerns. Only efficiency in prescription refills was significantly better than target values. Users wanted to print their information to share with their doctors, and questioned the value of MyHealtheVet search functions over existing online health information. In summary, PHR registration must balance simplicity and security, usability tests guide how PHRs can tailor functions to individual preferences, PHRs add value to users' data by making information more accessible and understandable, and healthcare organizations should build trust for PHR health content.

Jones, D. A., Shipman, J. P., Plaut, D. A., & Selden, C. R. (2010). Characteristics of personal health records: Findings of the Medical Library Association/National Library of Medicine Joint Electronic Personal Health Record Task Force. *Journal of the Medical Library Association*, 98(3), 243-249. doi:10.3163/1536-5050.98.3.013

OBJECTIVES: The Medical Library Association (MLA)/National Library of Medicine (NLM) Joint Electronic Personal Health Record Task Force examined the current state of personal health records (PHRs). METHODS: A working definition of PHRs was formulated, and a database was built with fields for specified PHR characteristics. PHRs were identified and listed. Each task force member was assigned a portion of the list for data gathering. Findings were recorded in the database. RESULTS: Of the 117 PHRs identified, 91 were viable. Almost half were standalone products. A number used national standards for nomenclature and/or record structure. Less than half were mobile device enabled. Some were publicly available, and others were offered only to enrollees of particular health plans or employees at particular institutions. A few were targeted to special health conditions. CONCLUSIONS: The PHR field is very dynamic. While most PHR products have some common elements, their features can vary. PHRs can link their users with librarians and information resources. MLA and NLM have taken an active role in making this connection and in encouraging librarians to assume this assistance role with PHRs.

Lee, M., Delaney, C., & Moorhead, S. (2006). Building a personal health record from nursing perspective. *Studies in Health Technology and Informatics*, 122, 25-29.

A complex set of needs-the increased accessibility to and interest in health information, more respected patients' rights, advanced information technologies, and

pressure to seek a cost-effective healthcare delivery-introduced the Personal Health Record (PHR). Nursing care, as essential to healthcare, must be represented in a PHR, but few studies have explored the nurses' role in the development and expansion of the PHR. Our 'IOWA PERSONAL HEALTH RECORD (IowaPHR)' would be a pioneer to demonstrate how nursing can be integrated in the PHR. IowaPHR is attributed with these innovations: (1) information that embraces main community health concerns; (2) transformation of a standardized nursing language into questions adjusted for consumer vocabulary level; and (3) a user-friendly interface equipped with trending of health conditions and a diary function. The usability of this PHR is validated by experts in terms of content, ease of navigation, time needed to complete tasks, ability to find desired information, and site presentation. This work will provide a way for nursing informatics to make a difference in health informatics.

Luo, G., Tang, C., & Thomas, S. B. (2011). Intelligent personal health record: Experience and open issues. *Journal of Medical Systems*, Mar 12 2011, Epub ahead of print.

doi:10.1007/s10916-011-9674-5

Web-based personal health records (PHRs) are under massive deployment. To improve PHR's capability and usability, we previously proposed the concept of intelligent PHR (iPHR). By introducing and extending expert system technology and Web search technology into the PHR domain, iPHR can automatically provide users with personalized healthcare information to facilitate their daily activities of living. Our iPHR system currently provides three functions: guided search for disease information, recommendation of home nursing activities, and recommendation of home medical products. This paper discusses our experience with iPHR as well as the

open issues, including both enhancements to the existing functions and potential new functions. We outline some preliminary solutions, whereas a main purpose of this paper is to stimulate future research work in the area of consumer health informatics.

Maloney, F. L., & Wright, A. (2010). USB-based Personal Health Records: An analysis of features and functionality. *International Journal of Medical Informatics*, 79(2), 97-111. doi:10.1016/j.ijmedinf.2009.11.005

PURPOSE: To determine the features of commercially available USB-based Personal Health Records (PHR) devices, and compare the commercial state of the art to recommendations made by certification committees. **METHODS:** Thirteen USB-based PHRs were identified and analyzed based on data elements used and features provided. Marketing techniques used by the companies were also explored. **RESULTS:** Eight of the thirteen PHRs contained all seven clinical data elements (problems, procedures, medications, providers, allergies, labs, immunizations), three were missing a single element and the remaining two lacked two elements. In the features analysis no single PHR contained all eight features (export data, import data, images, summary print out, emergency entry, teaching material available for problem, username and password supported, Mac-compatible), but two of the devices had seven of the eight features. Finally, scare tactics were used in marketing all but two of the PHR devices. **CONCLUSION:** While PHRs are very important in the health care field, at the present time, USB-based PHRs currently on the market appear to have deficiencies. Tethered or web-based PHRs may be a better option for consumers at present.

Marshall, P. (2009). Keeping tabs. How personal health records are changing the face of healthcare. *Marketing Health Services*, 29(4), 20-25.

The authors provide a definition for PHRs, use in health care, standards, objectives to achieve, and requirements for connecting care. The benefits of using a PHR are described. The authors also describe how to market the use of a PHR.

Mykkanen, J., Tuomainen, M., Luukkonen, I., & Itala, T. (2010). Analysis model for personal eHealth solutions and services. *Studies in Health Technology & Informatics*, 155, 205-211.

In this paper, we present a framework for analysing and assessing various features of personal wellbeing information management services and solutions such as personal health records and citizen-oriented eHealth services. The model is based on general functional and interoperability standards for personal health management applications and generic frameworks for different aspects of analysis. It has been developed and used in the MyWellbeing project in Finland to provide baseline for the research, development and comparison of many different personal wellbeing and health management solutions and to support the development of unified "Coper" concept for citizen empowerment.

Oftedahl, G., & Marshall, M. (2010). The future of personal health records: A summary of a roundtable discussion. *Minnesota Medicine*, 93(7), 50-52. Retrieved from <http://www.minnesotamedicine.com/PastIssues/PastIssues2010/July2010/ClinicalOfOftedahlJuly2010.aspx>

In 2009, the Institute for Clinical Systems Improvement held a roundtable on personal

health records (PHRs). Participants shared their thoughts about which features and functions are desired in a PHR, areas that need further exploration, and ways PHRs could make health care more efficient and effective. This article summarizes those discussions.

Or, C. K., Karsh, B. T., Severtson, D. J., Burke, L. J., Brown, R. L., & Brennan, P. F. (2011).

Factors affecting home care patients' acceptance of a web-based interactive self-management technology. *Journal of the American Medical Informatics Association*, 18(1), 51-59. doi:10.1136/jamia.2010.007336

OBJECTIVE: With the advent of personal health records and other patient-focused health technologies, there is a growing need to better understand factors that contribute to acceptance and use of such innovations. In this study, we employed the Unified Theory of Acceptance and Use of Technology as the basis for determining what predicts patients' acceptance (measured by behavioral intention) and perceived effective use of a web-based, interactive self-management innovation among home care patients. **DESIGN:** Cross-sectional secondary analysis of data from a randomized field study evaluating a technology-assisted home care nursing practice with adults with chronic cardiac disease. **MEASUREMENT AND ANALYSIS:** A questionnaire was designed based on validated measurement scales from prior research and was completed by 101 participants for measuring the acceptance constructs as part of the parent study protocol. Latent variable modeling with item parceling guided assessment of patients' acceptance. **RESULTS:** Perceived usefulness accounted for 53.9% of the variability in behavioral intention, the measure of acceptance. Together, perceived usefulness, health care knowledge, and behavioral intention accounted for

68.5% of the variance in perceived effective use. Perceived ease of use and subjective norm indirectly influenced behavioral intention, through perceived usefulness. Perceived ease of use and subjective norm explained 48% of the total variance in perceived usefulness. CONCLUSION: The study demonstrates that perceived usefulness, perceived ease of use, subjective norm, and healthcare knowledge together predict most of the variance in patients' acceptance and self-reported use of the web-based self-management technology.

Rocha, R. A., Romeo, A. N., & Norlin, C. (2007). Core features of a parent-controlled pediatric medical home record. *Studies in Health Technology and Informatics*, 129(Pt 2), 997-1001.

We describe a coordinated effort to identify the core features of a parent-controlled personal health record for children with special health care needs, involving parents, care givers, and healthcare providers. A summary of the core features is presented, emphasizing needs that are not commonly recognized as functions of a generic personal health record. Our goal was to identify requirements for personal records that empower parents to effectively obtain, organize, understand, and communicate the information necessary to help their children receive the best possible care.

Segall, N., Saville, J. G., L'Engle, P., Carlson, B., Wright, M. C., Schulman, K., & Tcheng, J. E. (2011). Usability evaluation of a personal health record. *AMIA Annual Symposium Proceedings, 2011*, 1233-1242.

The electronic personal health record (PHR) has been championed as a mediator of patient-centered care, yet its usability and utility to patients, key predictors of success,

have received little attention. Human-centered design (HCD) offers validated methods for studying systems effects on users and their cognitive tasks. In HCD, user-centered activities allow potential users to shape the design of the end product and enhance its usability. We sought to evaluate the usability and functionality of HealthView, the PHR of the Duke University Health System, using HCD methods. Study participants were asked to think aloud as they carried out tasks in HealthView. They then completed surveys and interviews eliciting their reactions to the web portal. Findings were analyzed to generate redesign recommendations, which will be incorporated in a future release of HealthView.

Sensmeier, J. E. (2010). The journey toward a personal health record. *Nursing Management*, 41(2), 47-50. doi:10.1097/01.NUMA.0000368568.05221.5a

The purpose of this article is to define what a PHR is and describe the benefits of a PHR. It includes considerations for selection and implementation of a PHR.

Siek, K. A., Ross, S. E., Khan, D. U., Haverhals, L. M., Cali, S. R., & Meyers, J. (2010). Colorado Care Tablet: The design of an interoperable Personal Health Application to help older adults with multimorbidity manage their medications. *Journal of Biomedical Informatics*, 43(5 Suppl), S22-6.

Medication errors are common and cause serious health issues during care transitions, particularly for older adults with multiple chronic conditions. In this paper, we discuss the design and evaluation of the Colorado Care Tablet, a Personal Health Application (PHA) that helps older adults and their lay caregivers manage their medication regimes during care transitions. We created a PHA that older adults with limited

computing experience could easily use by designing an application based on their real world artifacts and workflows.

Slagle, J. M., Gordon, J. S., Harris, C. E., Davison, C. L., Culpepper, D. K., Scott, P., & Johnson, K.

B. (2010). MyMediHealth - designing a next generation system for child-centered medication management. *Journal of Biomedical Informatics*, 43(5 Suppl), S27-31.

BACKGROUND: The last mile of the medication use system requires tools to help patients comply with medication administration rules and monitor for side effects.

Personal health records (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 healthcare 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. **DESIGN**

APPROACH: This project employed user-centered design to identify requirements for a child-centered medication management system. We collected information through site visits, facilitated group discussions, and iterative design sessions with adult caregivers.

Once design requirements were articulated and validated, we constructed an initial prototype medication scheduler, which was evaluated by 202 parents using scripted activities completed using an online interactive prototype. The results of this analysis informed the development of a working prototype. **STATUS:** We 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.

IMPLICATIONS: 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.

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Smolij, K., & Dun, K. (2006). Patient health information management: Searching for the right model. *Perspectives in Health Information Management*, 3, 10.

Accurate and timely health information is a crucial element in the medical decision making process during a medical encounter. Inadequate or misleading patient health information can lead to medical errors, inaccurate decision making, and increased cost. Providing physicians with access to every detail of a patient's medical history is difficult. Striking the balance between adequate and effective amounts of information is difficult. The Personal Health Record and Continuity of Care Record have emerged as concepts to support that balance. This paper reviews recently published literature on (1) approaches to personal health information management, (2) distinctions between terms and definitions describing patient health information, its format, its availability, and its accessibility, (3) guidelines, studies, or standards to support the rationale of patient information data elements that should be available to the provider for any medical encounter, and (4) identification of the most important needs for patient health information that should be addressed. The purpose of the review is to clarify the benefits and detriments of the different approaches as well as to provide some recommendations for the right model of patient health information management, focusing on the idea of the appropriate health information being available when needed.

Sox, C. M., Gribbons, W. M., Loring, B. A., Mandl, K. D., Batista, R., & Porter, S. C. (2010).

Patient-centered design of an information management module for a personally controlled health record. *Journal of Medical Internet Research*, 12(3), e36.

BACKGROUND: The development of health information technologies should be informed by iterative experiments in which qualitative and quantitative methodologies provide a deeper understanding of the abilities, needs, and goals of the target audience for a personal health application. **OBJECTIVE:** Our objective was to create an interface for parents of children with attention-deficit hyperactivity/disorder (ADHD) to enter disease-specific information to facilitate data entry with minimal task burden.

METHODS: We developed an ADHD-specific personal health application to support data entry into a personally controlled health record (PCHR) using a three-step, iterative process: (1) a needs analysis by conducting focus groups with parents of children with ADHD and an heuristic evaluation of a prerelease version of a PCHR, (2) usability testing of an initial prototype personal health application following a "think aloud" protocol, (3) performance testing of a revised prototype, and (4) finalizing the design and functionality of the ADHD personal health application. Study populations for the three studies (focus groups and two usability testing studies) were recruited from organizations in the greater Boston area. Study eligibility included being an English- or Spanish-speaking parent who was the primary caretaker of a school-age child with ADHD. We determined subjects' health literacy using the Test of Functional Health Literacy in Adults (TOFHLA). We assessed subjects' task burden using the National Aeronautics and Space Administration (NASA) Task Load Index. To assess the impact of factors associated with the time spent entering data, we calculated Pearson

correlation coefficients (r) between time on task and both task burden and subject characteristics. We conducted t tests to determine if time on task was associated with successful task completion. RESULTS: The focus groups included three cohorts: 4 Spanish-speaking parents with diverse health literacy, 4 English-speaking parents with lower health literacy, and 7 English-speaking parents with higher health literacy. Both the initial usability testing cohort ($n = 10$) and the performance-testing cohort ($n = 7$) included parents of diverse health literacy and ethnicity. In performance testing, the prototype PCHRs captured patient-specific data with a mean time on task of 11.9 minutes ($SD 6.5$). Task burden experienced during data entry was not associated with successful task completion ($P = .92$). Subjects' past computer experience was highly correlated with time on task ($r = .86, P = .01$), but not with task burden ($r = .18, P = .69$). The ADHD personal health application was finalized in response to these results by (1) simplifying the visual environment, (2) including items to support users limited by health literacy or technology experience, and (3) populating the application's welcome screen with pictures of culturally diverse families to establish a personal family-oriented look and feel. CONCLUSIONS: Our patient-centered design process produced a usable ADHD-specific personal health application that minimizes the burden of data entry.

Tang, P. C., Ash, J. S., Bates, D. W., Overhage, J. M., & Sands, D. Z. (2006). Personal health records: Definitions, benefits, and strategies for overcoming barriers to adoption. *Journal of the American Medical Informatics Association, 13*(2), 121-126.

doi:10.1197/jamia.M2025

Recently there has been a remarkable upsurge in activity surrounding the adoption of

personal health record (PHR) systems for patients and consumers. The biomedical literature does not yet adequately describe the potential capabilities and utility of PHR systems. In addition, the lack of a proven business case for widespread deployment hinders PHR adoption. In a 2005 working symposium, the American Medical Informatics Association's College of Medical Informatics discussed the issues surrounding personal health record systems and developed recommendations for PHR-promoting activities. Personal health record systems are more than just static repositories for patient data; they combine data, knowledge, and software tools, which help patients to become active participants in their own care. When PHRs are integrated with electronic health record systems, they provide greater benefits than would stand-alone systems for consumers. This paper summarizes the College Symposium discussions on PHR systems and provides definitions, system characteristics, technical architectures, benefits, barriers to adoption, and strategies for increasing adoption.

Tuil, W. S., Verhaak, C. M., De Vries Robbe, P. F., & Kremer, J. A. (2008). IVF patients show three types of online behaviour. *Human Reproduction (Oxford, England)*, *23*(11), 2501-2505. doi:10.1093/humrep/den275

BACKGROUND: The internet introduces new ways to deal with stress. However, it is unclear how its resources are used in everyday life. Using a web-based personal health record (PHR), we observed the patient's online behaviour and linked this to distress, theories on dealing with stress and demographics. METHODS: Between 2004 and 2007, all viewed web-pages were logged and categorized into 14 content types.

Behavioural styles were elicited using factor analysis. These behavioural styles were

subsequently correlated to data on demographics, coping mechanisms and distress from the female partner of the first 53 patient couples that used the PHR. RESULTS: One thousand and fifty patient couples viewed 588 887 web pages during their first treatment cycle. Factor analysis elicited three online behavioural styles explaining 66.9% of all variance in usage of the website: an 'individual information style', a 'generic information style' and a 'communication style'. The 'individual information style' correlated negatively to having paid employment (Spearman = -0.364, P = 0.007) and emotional coping mechanisms (Spearman = -0.305, P = 0.028). The 'communication style' correlated positively to having paid employment (Spearman = 0.318, P = 0.021) and anxiety (Spearman = 0.381, P = 0.005). CONCLUSIONS: IVF patients show three types of online behaviour. Only limited correlations exist between these styles and demographics, coping mechanisms or distress. When planning a website or portal for IVF patients, content should be adopted accordingly.

Tuomainen, M., & Mykkanen, J. (2011). Reference architecture of application services for personal wellbeing information management. *Studies in Health Technology and Informatics*, 169, 98-102.

Personal information management has been proposed as an important enabler for individual empowerment concerning citizens' wellbeing and health information. In the MyWellbeing project in Finland, a strictly citizen-driven concept of "Coper" and related architectural and functional guidelines have been specified. We present a reference architecture and a set of identified application services to support personal wellbeing information management. In addition, the related standards and developments are discussed.

Varroud-Vial, M. (2011). Improving diabetes management with electronic medical records.

Diabetes & Metabolism, 37(Suppl 4), S48-52. doi:10.1016/S1262-3636(11)70965-X

Most primary-care physicians have adopted electronic medical records (EMRs) for the management of patients in ambulatory care. Observational trials suggest that the use of EMRs improves the achievement of the recommended standards of diabetes care and intermediate outcomes. A French group of general practitioners has shown, in a randomized controlled trial of diabetes care, the beneficial effects of a follow-up module integrated into an EMR. Electronic reminders, eHealth technology and e-mail messaging to patients integrated into the EMR have also been reported to have a beneficial effect on diabetes care. Some recommendations have been devised for the meaningful use of EMRs to improve the process and, possibly, intermediate outcomes of diabetes care as well. Another potential benefit to consider is the extraction and aggregation of data to create diabetes registers. Large regional and national diabetes registers have been set up in the US and Europe for various purposes, including patient recall, description of care patterns and outcomes, improvement of practices, drug safety, observational research and retrospective trials. In France, the government initiative towards an Internet-based personal health record (PHR) provides an appropriate framework for implementing and sharing the information needed to improve diabetes care, such as electronic summaries of health information, personalized health plans (PHPs), and standardized and structured hospital-discharge forms. All of these materials can be generated from EMRs. The widespread and optimized use of EMRs for diabetes care with links to the national diabetes register and the capacity to supply PHRs are major considerations. Achieving these goals

requires a common initiative comprising primary care and diabetes scientific societies in cooperation with diabetes patients' associations.

Zeng-Treitler, Q., Goryachev, S., Kim, H., Keselman, A., & Rosendale, D. (2007). Making texts in electronic health records comprehensible to consumers: a prototype translator. *AMIA Annual Symposium Proceedings, 2007*, 846-850.

Narrative reports from electronic health records are a major source of content for personal health records. We designed and implemented a prototype text translator to make these reports more comprehensible to consumers. The translator identifies difficult terms, replaces them with easier synonyms, and generates and inserts explanatory texts for them. In feasibility testing, the application was used to translate 9 clinical reports. Majority (68.8%) of text replacements and insertions were deemed correct and helpful by expert review. User evaluation demonstrated a non-statistically significant trend toward better comprehension when translation is provided ($p=0.15$).

Financial and Political Drivers: Annotated Bibliography

Agarwal, R., & Khuntia, J. (2009). *(Personal Health Information and the Design of Consumer Health Information Technology: Background Report. (Prepared by Insight Policy Research under Contract No. HHS290200710072T). No. AHRQ Publication No.09-0075-EF)*. Rockville, MN: Agency for Healthcare Research and Quality.

The report was motivated by the growing emphasis on consumer-centric health care system and the desire to empower consumers in management of their health. It is a synthesis of the literature to define the domain of personal health information management (PHIM), summarize research on the topic, and make recommendations for better design of PHIM tools that provide value for users.

CMS (Centers for Medicare & Medicaid Services). (2012). *Medicare and Medicaid Programs; Electronic Health Record Incentive Program--Stage 2 [42 CFR Parts 412, 413, and 495]*. Retrieved April 15, 2012, from <http://www.health.state.mn.us/e-health/mustage2ehrcert.pdf>

This proposed rule would specify the Stage 2 criteria that eligible professionals (EPs), eligible hospitals, and critical access hospitals (CAHs) must meet in order to qualify for Medicare and/or Medicaid electronic health record (EHR) incentive payments. In addition, it would specify payment adjustments under Medicare for covered professional services and hospital services provided by EPs, eligible hospitals, and CAHs failing to demonstrate meaningful use of certified EHR technology and other program participation requirements. Included in Stage 2 MU are requirements for consumer engagement in access to their health information electronically and clinical

quality measures that support health information exchange across the continuum of care.

Department of Health and Human Services. (2012). *Health Information Technology: Standards, Implementation Specifications, and Certification Criteria for Electronic Health Record Technology, 2014 Edition; Revisions to the Permanent Certification Program for Health Information Technology [45 CFR Part 170]*. Retrieved April 15, 2012, from <http://federalregister.gov/a/2012-04430>

Under section 3004 of the Public Health Service Act, the Secretary of Health and Human Services is proposing to revise the initial set of standards, implementation specifications, and certification criteria adopted in an interim final rule published on January 13, 2010, and a subsequent final rule that was published on July 28, 2010, as well as to adopt new standards, implementation specifications, and certification criteria. The proposed new and revised certification criteria would establish the technical capabilities and specify the related standards and implementation specifications that Certified Electronic Health Record (EHR) Technology would need to include to, at a minimum, support the achievement of meaningful use by eligible professionals, eligible hospitals, and critical access hospitals under the Medicare and Medicaid EHR Incentive Programs beginning with the EHR reporting periods in fiscal year and calendar year 2014. This notice of proposed rulemaking also proposes revisions to the permanent certification program for health information technology, which includes changing the program's name. Included are the requirements to support consumer access to their information electronically.

Ford, E. W., Huerta, T. R., Schilhavy, R. A., & Menachemi, N. (2012). Effective US health system websites: Establishing benchmarks and standards for effective consumer engagement. *Journal of Healthcare Management*, 57(1), 47-64.

Hospitals and health systems are playing increasingly important roles as care coordination hubs and consumer information sources. In particular, the accountable care organization (ACO) and medical home models promoted in the Affordable Care Act place hospitals at the center of many activities related to health information exchange. Therefore, it is important for these organizations to have effective websites, and the need for a social media presence to connect with consumers is growing quickly. The purpose of this study is to assess the websites of hospitals and health systems on four dimensions: accessibility, content, marketing, and technology. In addition, an overall score is calculated to identify the top 25 hospital and health system websites. Specific website elements that healthcare managers can inspect visually are described for each dimension in the discussion section. Generally, hospital and health system websites can be more effective from an end user's perspective. In particular, hospitals and health systems lagged on the accessibility scale that measures the education level required to understand the language used on a site. The scale also assesses the extent to which web pages are designed for ease of movement from page to page using embedded links. Given that healthcare consumers come from every demographic and stratum of society, it is important that user-friendliness be optimized for a broadly defined audience. Hospital and health system websites can also be improved on the technology scale, as many sites do not return clear descriptions of

links to search engines such as Google and Bing that use web crawlers to collect information.

Hagland, M. (2011). Many mountains to climb. *Healthcare Informatics*, 28(10), 10-15.

Medical groups of all types and sizes stand collectively at a crossroads in the evolution of the healthcare industry in the United States at this point in time. Faced with a welter of issues, from reimbursement concerns to mandates coming out of federal healthcare reform and the American Recovery and Reinvestment/Health Information Technology for Economic and Clinical Health (ARRA-HITECH) Act and other legislative and regulatory developments and competing to better serve the needs of both patients and payers and purchasers, the CEOs, CIOs and others leading physician groups are working assiduously to find ways forward that meet the demands of stakeholder groups while also meeting the needs of their practicing physicians. In order to get a sense of where the leaders in the field are at this point in time. Healthcare Informatics Editor-in-Chief Mark Hagland gathered together several leaders of pioneering medical groups nationwide through a "virtual roundtable" process late this summer, in which he interviewed successive leaders and "shared forward" their thoughts with the others around this "virtual roundtable". Below are excerpts from the progressive interviews. Capsule profiles of the leaders and their organizations can be found below. Among the many issues facing these leaders: how to plan for the development of accountable care organizations (ACOs), the patient-centered medical home model, bundled payments and other federal policy requirements; how to make progress towards meaningful use, under the HITECH Act; how to plan for ongoing infrastructure, interoperability, and mobility development; and how to prioritize a variety of

disparate efforts aimed at fulfilling different types of needs. No one medical group leader has all the answers; but our panel of leaders certainly has many important and useful perspectives to share.

Hart, M. A. (2012). Accountable care organizations: The future of care delivery?. *American Journal of Nursing, 112*(2), 23-26.

This article provide a succinct description of accountable care organizations and the role of nursing. It provides an overview of the American Nurses' Association's testimony on ACOs. The importance of nursing involvement is emphasized referencing the IOM Future of Nursing report.

Korda, H., & Eldridge, G. N. (2011). Payment incentives and integrated care delivery: Levers for health system reform and cost containment. *Inquiry, 48*(4), 277-287.

The Patient Protection and Affordable Care Act encourages use of payment methods and incentives to promote integrated care delivery models including patient-centered medical homes, accountable care organizations, and primary care and behavioral health integration. These models rely on interdisciplinary provider teams to coordinate patient care; health information and other technologies to assure, monitor, and assess quality, and payment and financial incentives such as bundling, pay-for-performance, and gain-sharing to encourage value-based health care. In this paper, we review evidence about integrated care delivery, payment methods, and financial incentives to improve value in health care purchasing, and address how these approaches can be used to advance health system change.

Longworth, D. L. (2011). Accountable care organizations, the patient-centered medical home, and health care reform: What does it all mean?. *Cleveland Clinic Journal of Medicine*, 78(9), 571-582.

Medical care in the United States is plagued by extremely high costs, poor quality, and fragmented delivery. In response, new concepts of integrated health care delivery have developed, including patient-centered medical homes and accountable care organizations (ACOs). This article reviews these concepts and includes a detailed discussion of the Centers for Medicare and Medicaid Services' ACO and Shared Savings Proposed Rule.

NCQA. (2012). *Patient-centered medical care*. Retrieved April 15, 2012, from

<http://www.ncqa.org/tabid/631/default.aspx>

NCQA's Patient-Centered Medical Home (PCMH) 2011 is an innovative program for improving primary care. In a set of standards that describe clear and specific criteria, the program gives practices information about organizing care around patients, working in teams and coordinating and tracking care over time. The NCQA Patient-Centered Medical Home standards strengthen and add to the issues addressed by NCQA's original program. The Patient Centered Medical Home is a health care setting that facilitates partnerships between individual patients, and their personal physicians, and when appropriate, the patient's family. Care is facilitated by registries, information technology, health information exchange and other means to assure that patients get the indicated care when and where they need and want it in a culturally and linguistically appropriate manner.

Sensmeier, J., & Casey Halley, E. (2009). Connecting humans and health through health information exchange. *Studies in Health Technology and Informatics*, 146, 756-757.

To address healthcare quality, efficiency and safety, a national health information technology (IT) initiative was announced by the President of the United States in 2004 to make Electronic Health Records (EHR) available to most Americans within 10 years. The National Health IT Agenda has advanced with recognition of interoperability standards for Personal Health Records (PHR) and Population Health information exchange. This session will illustrate the national processes, timeline, stakeholders and benefits of adoption of interoperability standards to enable health information exchange.

Health Literacy: Annotated Bibliography

AHRQ (Agency for Healthcare Research and Quality). (2007). (*National healthcare disparities report*). Rockville, MD: AHRQ.

This 2007 report is the fifth *National Healthcare Disparities Report* (NHDR). It is produced by the Agency for Healthcare Research and Quality (AHRQ) on behalf of the U.S. Department of Health and Human Services (HHS) and in collaboration with an HHS-wide Interagency Work Group. The NHDR provides a comprehensive national overview of disparities in health care among racial, ethnic, and socioeconomic groups in the general U.S. population and within specific priority populations, and it tracks the progress of activities to reduce disparities. The NHDR tracks disparities related to the quality of and access to health care.

This fifth report attempts to answer the following question: Are we getting better at addressing disparities in the quality of and access to health care for priority populations in America? To do this, the report examines a set of 42 measures of quality and 8 measures of access. For each measure, the 2007 NHDR attempts to present a snapshot of the gaps between each racial, ethnic, and socioeconomic priority group and a comparison group. More importantly, where gaps exist, this report attempts to systematically discuss whether these gaps are getting bigger or smaller.

Measures of health care quality address the extent to which providers and hospitals deliver evidence-based care for specific services, as well as the outcomes of the care provided. They are organized around four dimensions of quality—effectiveness, patient safety, timeliness, and patient centeredness—and cover four stages of care—

staying healthy, getting better, living with illness or disability, and coping with the end of life. Measures of health care access include assessments of how easily patients are able to get needed health care and their actual use of services. They are organized around two dimensions of access—facilitators and barriers to care and health care utilization.

The NHDR is complemented by its companion report, the *National Healthcare Quality Report* (NHQR), which uses the same quality measures as the NHDR to provide a comprehensive overview of the quality of health care in America. Both reports measure health care quality and track changes over time, but with different orientations. The NHQR addresses the current state of health care quality and the opportunities for improvement for all Americans as a whole.

In the 2007 NHDR, three key themes emerge: Overall, disparities in health care quality and access are not getting smaller. Progress is being made, but many of the biggest gaps in quality and access have not been reduced. The problem of persistent uninsurance is a major barrier to reducing disparities.

Ancker, J. S., Barron, Y., Rockoff, M. L., Hauser, D., Pichardo, M., Szerencsy, A., & Calman, N. (2011). Use of an electronic patient portal among disadvantaged populations. *Journal of General Internal Medicine*, 26(10), 1117-1123.

BACKGROUND: Electronic patient portals give patients access to information from their electronic health record and the ability to message their providers. These tools are becoming more widely used and are expected to promote patient engagement with health care. OBJECTIVE: To quantify 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. DESIGN: Retrospective analysis of data from portal and electronic health records. PARTICIPANTS: 74,368 adult patients seen between April 2008 and April 2010. MAIN MEASURES: Odds of receiving an access code to the portal, activating the account, and using the portal more than once KEY RESULTS: Over the 2 years of the study, 16% of patients (n = 11,903) received an access code. Of these, 60% (n = 7138) activated the account, and 49% (n = 5791) used the account two or more times. Patients with chronic conditions were more likely to receive an access code and to become repeat users. In addition, the odds of receiving an access code were significantly higher for whites, women, younger patients, English speakers, and the insured. The odds of repeat portal use, among those with activated accounts, increased with white race, English language, and private insurance or Medicaid compared to no insurance. Racial disparities were small but persisted in models that controlled for language, insurance, and health status. CONCLUSIONS: We found good early rates of adoption and use of an electronic patient portal during the first 2 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.

Ancker, J. S., Chan, C., & Kukafka, R. (2009). Interactive graphics for expressing health risks: Development and qualitative evaluation. *Journal of Health Communication, 14*(5), 461-475.

Recent findings suggest that interactive game-like graphics might be useful in communicating probabilities. We developed a prototype for a risk communication module, focusing on eliciting users' preferences for different interactive graphics and assessing usability and user interpretations. Feedback from five focus groups was used to design the graphics. The final version displayed a matrix of square buttons; clicking on any button allowed the user to see whether the stick figure underneath was affected by the health outcome. When participants used this interaction to learn about a risk, they expressed more emotional responses, both positive and negative, than when viewing any static graphic or numerical description of a risk. Their responses included relief about small risks and concern about large risks. The groups also commented on static graphics: arranging the figures affected by disease randomly throughout a group of figures made it more difficult to judge the proportion affected but often was described as more realistic. Interactive graphics appear to have potential for expressing risk magnitude as well as the feeling of risk. This affective impact could be useful in increasing perceived threat of high risks, calming fears about low risks, or comparing risks. Quantitative studies are planned to assess the effect on perceived risks and estimated risk magnitudes.

Ancker, J. S., & Kaufman, D. (2007). Rethinking health numeracy: A multidisciplinary literature review. *Journal of the American Medical Informatics Association*, 14(6), 713-721.

The purpose of this review is to organize various published conceptions of health numeracy and to discuss how health numeracy contributes to the productive use of quantitative information for health. We define health numeracy as the individual-level

skills needed to understand and use quantitative health information, including basic computation skills, ability to use information in documents and non-text formats such as graphs, and ability to communicate orally. We also identify two other factors affecting whether a consumer can use quantitative health information: design of documents and other information artifacts, and health-care providers' communication skills. We draw upon the distributed cognition perspective to argue that essential ingredients for the productive use of quantitative health information include not only health numeracy but also good provider communication skills, as well as documents and devices that are designed to enhance comprehension and cognition. [References: 82]

Ancker, J. S., Kern, L. M., Abramson, E., & Kaushal, R. (2012). The Triangle Model for evaluating the effect of health information technology on healthcare quality and safety. *Journal of the American Medical Informatics Association*, 19(1), 61-65.

With the proliferation of relatively mature health information technology (IT) systems with large numbers of users, it becomes increasingly important to evaluate the effect of these systems on the quality and safety of healthcare. Previous research on the effectiveness of health IT has had mixed results, which may be in part attributable to the evaluation frameworks used. The authors propose a model for evaluation, the Triangle Model, developed for designing studies of quality and safety outcomes of health IT. This model identifies structure-level predictors, including characteristics of: (1) the technology itself; (2) the provider using the technology; (3) the organizational setting; and (4) the patient population. In addition, the model outlines process predictors, including (1) usage of the technology, (2) organizational support for and

customization of the technology, and (3) organizational policies and procedures about quality and safety. The Triangle Model specifies the variables to be measured, but is flexible enough to accommodate both qualitative and quantitative approaches to capturing them. The authors illustrate this model, which integrates perspectives from both health services research and biomedical informatics, with examples from evaluations of electronic prescribing, but it is also applicable to a variety of types of health IT systems.

Ancker, J. S., Weber, E. U., & Kukafka, R. (2011). Effect of arrangement of stick figures on estimates of proportion in risk graphics. *Medical Decision Making, 31*(1), 143-150.

BACKGROUND: Health risks are sometimes illustrated with stick figures, with a certain proportion colored to indicate they are affected by the disease. Perception of these graphics may be affected by whether the affected stick figures are scattered randomly throughout the group or arranged in a block. OBJECTIVE: . To assess the effects of stick-figure arrangement on first impressions of estimates of proportion, under a 10-s deadline. DESIGN: . Questionnaire. Participants and Setting. Respondents recruited online (n = 100) or in waiting rooms at an urban hospital (n = 65). Intervention. Participants were asked to estimate the proportion represented in 6 unlabeled graphics, half randomly arranged and half sequentially arranged. Measurements. Estimated proportions. RESULTS: . Although average estimates were fairly good, the variability of estimates was high. Overestimates of random graphics were larger than overestimates of sequential ones, except when the proportion was near 50%; variability was also higher with random graphics. Although the average inaccuracy was modest, it was large enough that more than one quarter of respondents confused 2

graphics depicting proportions that differed by 11 percentage points. Low numeracy and educational level were associated with inaccuracy. Limitations. Participants estimated proportions but did not report perceived risk. CONCLUSIONS: . Randomly arranged arrays of stick figures should be used with care because viewers' ability to estimate the proportion in these graphics is so poor that moderate differences between risks may not be visible. In addition, random arrangements may create an initial impression that proportions, especially large ones, are larger than they are.

Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., . . .

Viswanathan, M. (2011). (*Health literacy interventions and outcomes: An updated systematic review*. No. Evidence Report/Technology Assessment No. 199.). Rockville, MD.: Agency for Healthcare Research and Quality.

Objectives. To update a 2004 systematic review of health care service use and health outcomes related to differences in health literacy level and interventions designed to improve these outcomes for individuals with low health literacy. Disparities in health outcomes and effectiveness of interventions among different sociodemographic groups were also examined.

Data sources. We searched MEDLINE,[®] the Cumulative Index to Nursing and Allied Health Literature, the Cochrane Library, PsychINFO, and the Educational Resources Information Center. For health literacy, we searched using a variety of terms, limited to English and studies published from 2003 to May 25, 2010. For numeracy, we searched from 1966 to May 25, 2010.

Review methods. We used standard Evidence-based Practice Center methods of dual review of abstracts, full-text articles, abstractions, quality ratings, and strength of

evidence grading. We resolved disagreements by consensus. We evaluated whether newer literature was available for answering key questions, so we broadened our definition of health literacy to include numeracy and oral (spoken) health literacy. We excluded intervention studies that did not measure health literacy directly and updated our approach to evaluate individual study risk of bias and to grade strength of evidence.

Conclusions. The field of health literacy has advanced since the 2004 report. Future research priorities include justifying appropriate cutoffs for health literacy levels prior to conducting studies; developing tools that measure additional related skills, particularly oral (spoken) health literacy; and examining mediators and moderators of the effect of health literacy. Priorities in advancing the design features of interventions include testing novel approaches to increase motivation, techniques for delivering information orally or numerically, “work around” interventions such as patient advocates; determining the effective components of already-tested interventions; determining the cost-effectiveness of programs; and determining the effect of policy and practice interventions.

Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., & Crotty, K. (2011). Low health literacy and health outcomes: An updated systematic review. *Annals of Internal Medicine*, 155(2), 97-107.

BACKGROUND: Approximately 80 million Americans have limited health literacy, which puts them at greater risk for poorer access to care and poorer health outcomes.

PURPOSE: To update a 2004 systematic review and determine whether low health literacy is related to poorer use of health care, outcomes, costs, and disparities in

health outcomes among persons of all ages. DATA SOURCES: English-language articles identified through MEDLINE, CINAHL, PsycINFO, ERIC, and Cochrane Library databases and hand-searching (search dates for articles on health literacy, 2003 to 22 February 2011; for articles on numeracy, 1966 to 22 February 2011). STUDY SELECTION: Two reviewers independently selected studies that compared outcomes by differences in directly measured health literacy or numeracy levels. DATA EXTRACTION: One reviewer abstracted article information into evidence tables; a second reviewer checked information for accuracy. Two reviewers independently rated study quality by using predefined criteria, and the investigative team jointly graded the overall strength of evidence. DATA SYNTHESIS: 96 relevant good- or fair-quality studies in 111 articles were identified: 98 articles on health literacy, 22 on numeracy, and 9 on both. Low health literacy was consistently associated with more hospitalizations; greater use of emergency care; lower receipt of mammography screening and influenza vaccine; poorer ability to demonstrate taking medications appropriately; poorer ability to interpret labels and health messages; and, among elderly persons, poorer overall health status and higher mortality rates. Poor health literacy partially explains racial disparities in some outcomes. Reviewers could not reach firm conclusions about the relationship between numeracy and health outcomes because of few studies or inconsistent results among studies. LIMITATIONS: Searches were limited to articles published in English. No Medical Subject Heading terms exist for identifying relevant studies. No evidence concerning oral health literacy (speaking and listening skills) and outcomes was found. CONCLUSION: Low health literacy is

associated with poorer health outcomes and poorer use of health care services.

PRIMARY FUNDING SOURCE: Agency for Healthcare Research and Quality.

Boren, S. A. (2009). A review of health literacy and diabetes: Opportunities for technology. *Journal of Diabetes Science & Technology*, 3(1), 202-209.

BACKGROUND: The objective of this study was to assess the published literature on health literacy and diabetes, as well as identify opportunities for technology to strengthen information skills and modify behavior to improve diabetes health outcomes. METHODS: Medline (1990-2008), the Cumulative Index to Nursing and Allied Health Literature (1990-2008), and the Education Resources Information Center (1990-2008) were searched, and reference lists from included articles were reviewed to identify additional studies. Articles were included that presented measures of literacy or numeracy specific to diabetes, examined associations between health literacy and diabetes outcomes, or tested a health literacy intervention among persons with diabetes. RESULTS: Twenty-four articles were included in this review. Five articles reported on measures of literacy or numeracy specific to diabetes. Thirteen of the fifteen cross-sectional studies (87%) associated limited health literacy with poorer diabetes outcomes. Two of the four (50%) health literacy intervention studies lead to improved health outcomes. CONCLUSIONS: The cross-sectional studies provide evidence of an association between health literacy and diabetes outcomes; however, there is a need to design and test strategies to improve diabetes health outcomes that consider health literacy. Information and communication technology opportunities could help to mediate the effect that limited health literacy has on diabetes-related health outcomes. Copyright Diabetes Technology Society

Car, J., Lang, B., Colledge, A., Ung, C., & Majeed, A. (2011). Interventions for enhancing consumers' online health literacy. *Cochrane Database of Systematic Reviews*, (6), 007092.

BACKGROUND: Access to health information is critical to enable consumers to participate in decisions on health. Increasingly, such information is accessed via the internet, but a number of barriers prevent consumers making effective use of it. These barriers include inadequate skills to search, evaluate and use the information. It has not yet been demonstrated whether training consumers to use the internet for health information can result in positive health outcomes. **OBJECTIVES:** To assess the effects of interventions for enhancing consumers' online health literacy (skills to search, evaluate and use online health information). **SEARCH STRATEGY:** We searched: the Cochrane Consumers and Communication Review Group Specialised Register; Cochrane Central Register of Controlled Trials (CENTRAL, The Cochrane Library, Issue 1 2008); MEDLINE (Ovid); EMBASE (Ovid); CINAHL (Dialog); ERIC (CSA Illumina); LISA (CSA Illumina); PsycINFO (Ovid); Index to scientific and technical proceedings; SIGLE; ASLIB Index to Theses; ProQuest Dissertation Abstracts; National Research Register/UK CRN Portfolio database; Current Controlled Trials - MetaRegister of Controlled Trials. We searched all databases for the period January 1990 to March 2008. **SELECTION CRITERIA:** Randomised controlled trials (RCTs), cluster RCTs and associated economic evaluations, quasi-RCTs, interrupted time series analyses, and controlled before and after (CBA) studies assessing interventions to enhance consumers' online health literacy, in any language. **DATA COLLECTION AND ANALYSIS:** Two review authors independently selected studies for inclusion, assessed their

quality and extracted data. We contacted study authors for clarification and to seek missing data. We presented results as a narrative and tabular summary, and calculated mean differences where appropriate. MAIN RESULTS: We included two studies: one randomised controlled trial (RCT) and one controlled before and after (CBA) study with a combined total of 470 participants. The RCT compared internet health information classes with patient education classes for participants with HIV infection. Only the RCT, which we rated as having a moderate risk of bias, reported statistically significant positive effects for primary outcomes related to online health literacy in the intervention group, for the following outcomes: 'Self-efficacy for health information seeking', 'health information evaluation skills' and the 'number of times the patient discussed online information with a health provider'. The CBA, which we rated as having a high risk of bias, compared internet health information classes with a control group receiving no intervention among healthy adults aged 50+. It showed significant positive changes only in a secondary (behavioural) outcome in the intervention group, regarding the readiness to adopt the internet as a tool for preventive health information. No adverse effects were reported. There is low quality evidence that such interventions may improve some outcomes relevant to online health literacy in certain populations. AUTHORS' CONCLUSIONS: Due to the small number of studies and their variable methodological quality, the evidence is too weak to draw any conclusions about implications for the design and delivery of interventions for online health literacy. There is a need for well-designed RCTs to investigate the effects of such interventions. These should involve different participants (in terms of disease status, age, socio-economic group and gender) to analyse the extent to which online health

literacy reduces a barrier to using the internet for health information. Trials should be conducted in different settings and should examine interventions to enhance consumers' online health literacy (search, appraisal and use of online health information) like internet training courses, measuring outcomes up to at least one year after the intervention to estimate the sustainability of the intervention effects.

Cavanaugh, K., Huizinga, M. M., Wallston, K. A., Gebretsadik, T., Shintani, A., Davis, D., . . .

Rothman, R. L. (2008). Association of numeracy and diabetes control. *Annals of Internal Medicine*, 148(10), 737-746.

BACKGROUND: The influence of a patient's quantitative skills (numeracy) on the management of diabetes is only partially understood. **OBJECTIVE:** To examine the association between diabetes-related numeracy and glycemic control and other diabetes measurements. **DESIGN:** Cross-sectional survey. **SETTING:** 2 primary care and 2 diabetes clinics at 3 medical centers. **PARTICIPANTS:** 398 adult patients with type 1 or type 2 diabetes mellitus enrolled between March 2004 and November 2005.

MEASUREMENTS: Health literacy, general numeracy, and diabetes-related numeracy assessed by using the Rapid Estimate of Adult Literacy in Medicine; the Wide Range Achievement Test, 3rd edition; and the Diabetes Numeracy Test (DNT), respectively.

The primary outcome was most recent level of hemoglobin A1c. Additional measurements were diabetes knowledge, perceived self-efficacy of diabetes self-management, and self-management behaviors. **RESULTS:** The median DNT score was 65% (interquartile range, 42% to 81%). Common errors included misinterpreting glucose meter readings and miscalculating carbohydrate intake and medication dosages. Lower DNT scores were associated with older age, nonwhite race, fewer years

of education, lower reported income, lower literacy and general numeracy skills, lower perceived self-efficacy, and selected self-management behaviors. Patients scoring in the lowest DNT quartile (score <42%) had a median hemoglobin A1c level of 7.6% (interquartile range, 6.5% to 9.0%) compared with 7.1% (interquartile range, 6.3% to 8.1%) in those scoring in the highest quartile (P = 0.119 for trend). A regression analysis adjusted for age, sex, race, income, and other factors found a modest association between DNT score and hemoglobin A1c level. LIMITATION: Causality cannot be determined in this cross-sectional study, especially with its risk for unmeasured confounding variables. CONCLUSION: Poor numeracy skills were common in patients with diabetes. Low diabetes-related numeracy skills were associated with worse perceived self-efficacy, fewer self-management behaviors, and possibly poorer glycemic control.

CDC (Centers for Disease Control and Prevention). (2011). *Learn about health literacy*.

Retrieved April 17, 2012, from <http://www.cdc.gov/healthliteracy/Learn/index.html>

The year 2010 was a tipping point for health literacy to enter the mainstream of health policy. Health literacy is part of the Patient Protection and Affordable Care Act, i.e. "health reform," the most significant change to health policy in decades.

The field "tipped" because we had strong momentum from Healthy People, the Institute of Medicine, and the National Action Plan to Improve Health Literacy. Our work is reinforced by new federal plain language legislation – the Plain Writing Act of 2010.

The web site will deliver information and resources on current activities in health literacy research, practice and evaluation for public health. Specifically, this site aims

to bring you new and timely information about CDC's work to improve health literacy and highlight the work of others who are implementing the goals and strategies of the National Action Plan to Improve Health Literacy.

The web site includes a blog to generate and continue discussions that will help all of us. The blog is one way to share ideas about what you would like to see CDC and other public health agencies do to improve health literacy.

CDC (Centers for Disease Control and Prevention). (2009). *Improving health literacy for older adults: Expert panel report*. Retrieved April 19, 2012, from <http://www.cdc.gov/healthliteracy/Learn/pdf/olderadults.pdf>

This report summarizes the presentations and discussions of the expert panel convened by NCHM. The 12 panelists, all of whom came from outside CDC, were selected because of their expertise in the health information needs, preferences, and capacities of older adults.

Chan, C. V., & Kaufman, D. R. (2011). A framework for characterizing eHealth literacy demands and barriers. *Journal of Medical Internet Research*, 13(4), e94.
doi:10.2196/jmir.1750

BACKGROUND: Consumer eHealth interventions are of a growing importance in the individual management of health and health behaviors. However, a range of access, resources, and skills barriers prevent health care consumers from fully engaging in and benefiting from the spectrum of eHealth interventions. Consumers may engage in a range of eHealth tasks, such as participating in health discussion forums and entering information into a personal health record. eHealth literacy names a set of skills and

knowledge that are essential for productive interactions with technology-based health tools, such as proficiency in information retrieval strategies, and communicating health concepts effectively. **OBJECTIVE:** We propose a theoretical and methodological framework for characterizing complexity of eHealth tasks, which can be used to diagnose and describe literacy barriers and inform the development of solution strategies. **METHODS:** We adapted and integrated two existing theoretical models relevant to the analysis of eHealth literacy into a single framework to systematically categorize and describe task demands and user performance on tasks needed by health care consumers in the information age. The method derived from the framework is applied to (1) code task demands using a cognitive task analysis, and (2) code user performance on tasks. The framework and method are applied to the analysis of a Web-based consumer eHealth task with information-seeking and decision-making demands. We present the results from the in-depth analysis of the task performance of a single user as well as of 20 users on the same task to illustrate both the detailed analysis and the aggregate measures obtained and potential analyses that can be performed using this method. **RESULTS:** The analysis shows that the framework can be used to classify task demands as well as the barriers encountered in user performance of the tasks. Our approach can be used to (1) characterize the challenges confronted by participants in performing the tasks, (2) determine the extent to which application of the framework to the cognitive task analysis can predict and explain the problems encountered by participants, and (3) inform revisions to the framework to increase accuracy of predictions. **CONCLUSIONS:** The results of this illustrative application suggest that the framework is useful for characterizing task

complexity and for diagnosing and explaining barriers encountered in task completion. The framework and analytic approach can be a potentially powerful generative research platform to inform development of rigorous eHealth examination and design instruments, such as to assess eHealth competence, to design and evaluate consumer eHealth tools, and to develop an eHealth curriculum.

Chinn, D. (2011). Critical health literacy: A review and critical analysis. *Social Science & Medicine*, 73(1), 60-67.

Though there has been a considerable expansion of interest in the health literacy concept worldwide, there has also been criticism that this concept has been poorly defined, that it stretches the idea of "literacy" to an indefensible extent and more specifically, that it adds little to the existing concerns and intervention approaches of the better established discipline of health promotion. This paper takes as a starting point the expanded model of health literacy advanced by Nutbeam (2000) and addresses these concerns by interrogating the concept of "critical health literacy" in order to draw conclusions about its utility for advancing the health of individuals and communities. The constituent domains of critical health literacy are identified; namely information appraisal, understanding the social determinants of health, and collective action, and as far as possible each are clearly delineated, with links to related concepts made explicit. The paper concludes that an appreciation of work undertaken in a range of different disciplines, such as media studies, medical sociology, and evidence-based medicine can enhance our understanding of the critical health literacy construct and help us understand its usefulness as a social asset which helps individuals towards a critical engagement with health information. There is some evidence that aspects of

critical health literacy have indeed been found to be a resource for better health outcomes, but more research is needed in this area, both to develop quantitative and qualitative approaches to evaluating health literacy skills, and to offer convincing evidence that investment in programmes designed to enhance critical health literacy are worthwhile. Copyright Copyright 2011 Elsevier Ltd. All rights reserved.

Coleman, C. (2011). Teaching health care professionals about health literacy: A review of the literature. *Nursing Outlook*, 59(2), 70-78.

Low health literacy is a common and serious issue in U.S. health care. Health care professionals lack adequate training in health literacy principles. Increasing and improving health literacy training for the health care workforce is needed. Health professions educators have responded to this need by developing health literacy curricula, which use a wide variety of didactic and experiential teaching techniques and tools. This article reviews the literature on teaching health literacy principles to health professionals and presents a menu of teaching options for health professions educators. Copyright Copyright 2011 Elsevier Inc. All rights reserved.

Easton, P., Entwistle, V. A., & Williams, B. (2010). Health in the 'hidden population' of people with low literacy. A systematic review of the literature. *BMC Public Health*, 10, 459.

BACKGROUND: Much of the evidence of an association between low functional or health literacy and poor health comes from studies that include people who have various cognitive difficulties or who do not speak the dominant language of their society. Low functional or health literacy among these people is likely to be evident in

spoken conversation. However, many other people can talk readily about health and other issues but have problems using written information. Consequently, their difficulties may be far less evident to healthcare professionals, creating a 'hidden population' whose functional or health literacy problems have different implications because they are less likely to be recognised and addressed. We aimed to review published research to investigate relationships between low functional or health literacy and health in working age adults who can converse in the dominant language but have difficulty with written language. METHODS: We searched reviews and electronic databases for studies that examined health-related outcomes among the population of interest. We systematically extracted data relating to relationships between low functional or health literacy and both health status and various possible mediators or moderators of the implications of literacy for health. We developed a narrative review. RESULTS: Twenty-four studies met our inclusion criteria. Lower functional or health literacy in this population was found to be associated with worse health status. This may be mediated by difficulties accessing healthcare, and poorer self-management of health problems. It is currently unclear whether, how or to what extent these difficulties are mediated by poorer knowledge stemming from low functional or health literacy. The variation in functional or health literacy measures and comparisons make it difficult to compare study findings and to establish the implications of different literacy issues for health outcomes. CONCLUSIONS: There is evidence in the literature that low functional or health literacy is associated with poor health in the 'hidden population' of adults whose literacy difficulties may not be evident to health care providers. Further research is needed to help understand the

particular disadvantages faced by this population and to establish appropriate responses.

Eichler, K., Wieser, S., & Brugger, U. (2009). The costs of limited health literacy: A systematic review. *International Journal of Public Health, 54*(5), 313-324.

OBJECTIVES: To summarize evidence about (1) the costs of limited health literacy (HL) and (2) the cost-effectiveness of interventions to improve limited HL. METHODS: We performed a systematic review searching electronic databases and additional information resources. We included observational studies and interventional studies with HL-outcomes. We included populations at high risk for low HL and patients with (1) diabetes mellitus or (2) hyperlipidemia. RESULTS: We retrieved 2,340 papers and included 10 studies for analysis. The prevalence of limited HL is considerable (range 34-59%). On the health system level, the additional costs of limited HL range from 3 to 5% of the total health care cost per year. On the patient level, the additional expenditures per year per person with limited HL compared to persons with adequate HL range from US \$143 to 7,798. Data on the cost-effectiveness of interventions to improve limited HL are scarce. CONCLUSION: The costs of limited HL may be substantial, but few studies were retrieved and the results are heterogeneous.

[References: 30]

Eshet-Alkalai, Y., & Chajut, E. (2009). Changes Over Time in Digital Literacy.

CyberPsychology & Behavior, 12(6), 713-715. doi:10.1089/cpb.2008.0264

The current study is a follow-up on the 2002 empirical study by Eshet-Alkalai and Amichai-Hamburger, which investigated digital literacy skills among different age

groups. This study explores changes through time in digital literacy among the same participants 5 years later, and their performance is compared to new matched control groups. Results indicate an improvement over time among all age groups, but especially for the adults, in the tasks that require proficiency and technical control in using technology (e.g., photovisual and branching literacy skills). On the other hand, results indicate a drop in the skills that require creative and critical thinking (e.g., information and reproduction literacy skills), especially for the younger participants. Results show two major patterns of change over time: (a) closing the gap between younger and older participants in the tasks that emphasize proficiency and technical control and (b) widening the gap between younger and older participants in tasks that emphasize creativity and critical thinking. Based on the comparison with the matched control groups, we suggest that experience with technology, and not age, accounts for the observed lifelong changes in digital literacy skills. [ABSTRACT FROM AUTHOR]; Copyright of CyberPsychology & Behavior is the property of Mary Ann Liebert, Inc. and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use. This abstract may be abridged. No warranty is given about the accuracy of the copy. Users should refer to the original published version of the material for the full abstract. (Copyright applies to all Abstracts.)

Evangelista, L. S., Rasmusson, K. D., Laramée, A. S., Barr, J., Ammon, S. E., Dunbar, S., . . .

Yancy, C. W. (2010). Health literacy and the patient with heart failure--implications for patient care and research: A consensus statement of the Heart Failure Society of

America. *Journal of Cardiac Failure*, 16(1), 9-16.

BACKGROUND: Low health literacy compromises patient safety, quality health care, and desired health outcomes. Specifically, low health literacy is associated with decreased knowledge of one's medical condition, poor medication recall, nonadherence to treatment plans, poor self-care behaviors, compromised physical and mental health, greater risk of hospitalization, and increased mortality. **METHODS:** The health literacy literature was reviewed for: definitions, scope, risk factors, assessment, impact on health outcomes (cardiovascular disease and heart failure), and interventions. Implications for future research and for clinical practice to address health literacy in heart failure patients were summarized. **RESULTS:** General health literacy principles should be applied to patients with heart failure, similar to others with chronic conditions. Clinicians treating patients with heart failure should address health literacy using five steps: recognize the consequences of low health literacy, screen patients at risk, document literacy levels and learning preferences, and integrate effective strategies to enhance patients' understanding into practice. **CONCLUSION:** Although the literature specifically addressing low health literacy in patients with heart failure is limited, it is consistent with the larger body of health literacy evidence. Timely recognition of low health literacy combined with tailored interventions should be integrated into clinical practice. [References: 60]

Fagerlin, A., Zikmund-Fisher, B. J., Ubel, P. A., Jankovic, A., Derry, H. A., & Smith, D. M. (2007). Measuring numeracy without a math test: Development of the Subjective Numeracy Scale. *Medical Decision Making*, 27(5), 672-680.

BACKGROUND: Basic numeracy skills are necessary before patients can understand

the risks of medical treatments. Previous research has used objective measures, similar to mathematics tests, to evaluate numeracy. OBJECTIVES: To design a subjective measure (i.e., self-assessment) of quantitative ability that distinguishes low- and high-numerate individuals yet is less aversive, quicker to administer, and more usable for telephone and Internet surveys than existing numeracy measures.

RESEARCH DESIGN: Paper-and-pencil questionnaires. SUBJECTS: The general public (N = 703) surveyed at 2 hospitals. MEASURES: Forty-nine subjective numeracy questions were compared to measures of objective numeracy. RESULTS: An 8-item measure, the Subjective Numeracy Scale (SNS), was developed through several rounds of testing. Four items measure people's beliefs about their skill in performing various mathematical operations, and 4 measure people's preferences regarding the presentation of numerical information. The SNS was significantly correlated with Lipkus and others' objective numeracy scale (correlations: 0.63-0.68) yet was completed in less time (24 s/item v. 31 s/item, $P < 0.05$) and was perceived as less stressful (1.62 v. 2.69, $P < 0.01$) and less frustrating (1.92 v. 2.88, $P < 0.01$). Fifty percent of participants who completed the SNS volunteered to participate in another study, whereas only 8% of those who completed the Lipkus and others scale similarly volunteered (odds ratio = 11.00, 95% confidence interval = 2.14-56.65).

CONCLUSIONS: The SNS correlates well with mathematical test measures of objective numeracy but can be administered in less time and with less burden. In addition, it is much more likely to leave participants willing to participate in additional research and shows much lower rates of missing or incomplete data.

Golbeck, A. L., Ahlers-Schmidt, C. R., Paschal, A. M., & Dismuke, S. E. (2005). A definition and operational framework for health numeracy. *American Journal of Preventive Medicine*, 29(4), 375-376.

Health numeracy has often been overshadowed by health literacy, either ignored completely or identified simply as a subset of health literacy. Only now are researchers beginning to realize the importance of health numeracy as a separate entity. One of the first steps in this evolution is to establish a distinct definition for health numeracy, something that has not been addressed in the literature to date. This paper proposes such a definition, as well as a set of clarifying categories in hopes of helping researchers both to advance the field of health numeracy and to focus their topics within the realm of health numeracy.

Greene, J., Peters, E., Mertz, C. K., & Hibbard, J. H. (2008). Comprehension and choice of a consumer-directed health plan: An experimental study. *American Journal of Managed Care*, 14(6), 369-376.

Objectives: To examine the extent to which numeracy predicts consumer-directed health plan (CDHP) comprehension and health plan choice. Also, to test whether comprehension can be improved using different presentation approaches.

Study Design: We conducted an experimental laboratory study in which 303 adults viewed information about a hypothetical CDHP and a hypothetical preferred provider organization (PPO) presented in several different ways. Participants were randomized to view plan comparisons in a side-by-side or a common/unique format, and whether or not to view a framework.

Methods: Participants completed a survey that included comprehension items,

numeracy and literacy assessments, and sociodemographics. Multivariate regression models were developed to examine the independent effects of numeracy and presentation approach on CDHP comprehension

and choice. Interactions between numeracy and presentation approaches were tested.

Results: Although less numerate consumers understood less about CDHPs, they were substantially more likely to select the CDHP. Providing an overarching framework to highlight the differences between the CDHP and PPO boosted comprehension on items related to the framework message. However, it reduced comprehension on items that were not related to the framework, particularly among the less numerate. Participants reported that the common/unique

presentation of comparative information was easier to understand, yet there was a trend toward less comprehension using that presentation approach.

Conclusions: This study highlights the difficulty many consumers have in understanding comparative plan information and in making informed healthcare choices. Findings also indicate that some presentation strategies may help the less skilled understand choices better.

Hawkins, A. O., Kantayya, V. S., & Sharkey-Asner, C. (2010). Health literacy: A potential barrier in caring for underserved populations. *Disease-A-Month*, 56(12), 734-740.

The article summarizes the prevalence of health literacy, costs, and outcomes. Specific recommendations are included for improving health literacy.

Herndon, J. B., Chaney, M., & Carden, D. (2011). Health literacy and emergency department outcomes: A systematic review. *Annals of Emergency Medicine*, 57(4), 334-345.

STUDY OBJECTIVE: We assess emergency department (ED) patients' health literacy, the readability of ED patient materials, and the relationship between health literacy and ED outcomes through a systematic literature review. METHODS: PubMed, PsychInfo, CINAHL, Web of Knowledge, and ERIC were searched for studies published January 1, 1980, to July 15, 2010, conducted in the United States, reporting original data, and measuring ED patients' health literacy, the readability of ED materials, or the association between health literacy and ED-related outcomes. Two reviewers evaluated each study and abstracted information from included studies into evidence tables. RESULTS: We identified 413 articles, and 31 met inclusion criteria. Collectively, health literacy skills were assessed at or below the eighth-grade level for approximately 40% of ED patients. In contrast, ED patient materials were typically assessed at or above the ninth-grade level. Studies of adults aged 65 years and older found that those with lower health literacy were more likely to use the ED and incur higher ED costs. Studies of pediatric ED patients did not find direct effects of caregiver literacy on ED outcomes. CONCLUSION: A substantial proportion of ED patients have limited health literacy, and ED materials are typically too complex for these patients. It is important for EDs to evaluate the accessibility and patient understanding of information presented. The evidence linking health literacy to ED outcomes is limited. Additional research is needed to better understand the relationship between health literacy and ED outcomes. Copyright Copyright 2010 American College of Emergency Physicians. Published by Mosby, Inc. All rights reserved.

HRSA. *About health literacy*. Retrieved December 26, 2011, from

<http://www.hrsa.gov/publichealth/healthliteracy/healthlitabout.html>

This website provides a definition for health literacy, prevalence, consequences of low health literacy, and what providers can do. It also provides links to other resources

IOM (Institute of Medicine). (2004). *Health Literacy: A Prescription to End Confusion*.

Washington, DC: National Academies Press.

Health literacy--the ability for individuals to obtain, process, and understand basic health information and services to facilitate appropriate health decisions--is increasingly recognized as an important facet of health care and health outcomes.

Although research on health literacy has grown tremendously in the past decade, there is no widely agreed-upon framework for health literacy as a determinant of health outcomes. Most instruments focus on assessing an individual's health literacy, yet the scope of health literacy reaches far beyond an individual's skills and abilities. Health literacy occurs in the context of the health care system, and therefore measures of health literacy must also assess the demands and complexities of the health care systems with which patients interact. For example, measures are needed to determine how well the system has been organized so that it can be navigated by individuals with different levels of health literacy and how well health organizations are doing at making health information understandable and actionable.

To examine what is known about measures of health literacy, the Institute of Medicine convened a workshop. The workshop, summarized in this volume, reviews the current status of measures of health literacy, including those used in the health care setting; discusses possible surrogate measures that might be used to assess health literacy; and

explores ways in which health literacy measures can be used to assess patient-centered approaches to care.

IOM (Institute of Medicine). (2009). *Measures of Health Literacy: Workshop Summary*. Washington, DC: The National Academies Press.

The Institute of Medicine Roundtable on Health Literacy serves to educate the public, press, and policy makers regarding issues of health literacy. To examine what is known about measures of health literacy, the Roundtable convened a planning committee to develop a workshop agenda that would address the following issues:

- The current status of measures of health literacy, including those used in the health care setting;
- Possible surrogate measures that might be used to assess health literacy; and
- Ways in which health literacy measures can be used to assess patient-centered approaches to care.

IOM (Institute of Medicine). (2011). *Improving health literacy within a state: Workshop summary* [http://www.nap.edu/catalog.php?record_id=13185]. Washington, DC: The National Academies Press.

Health literacy is the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions. According to *Health Literacy: A Prescription to End Confusion* (IOM, 2004), nearly half of all American adults--90 million people--have inadequate health literacy to navigate the healthcare system.

To address issues raised in that report, the Institute of Medicine convened the

Roundtable on Health Literacy, which brings together leaders from the federal government, foundations, health plans, associations, and private companies to discuss challenges facing health literacy practice and research and to identify approaches to promote health literacy in both the public and private sectors. On November 30, 2010, the roundtable cosponsored a workshop with the University of California, Los Angeles (UCLA), Anderson School of Management in Los Angeles.

Improving Health Literacy Within a State serves as a summary of what occurred at the workshop. The workshop focused on understanding what works to improve health literacy across a state, including how various stakeholders have a role in improving health literacy. The focus of the workshop was on presentations and discussions that address (1) the clinical impacts of health literacy improvement approaches; (2) economic outcomes of health literacy implementation; and (3) how various stakeholders can affect health literacy.

Kern, L. M., Ancker, J. S., Abramson, E., Patel, V., Dhopeswarkar, R. V., & Kaushal, R. (2011).

Evaluating health information technology in community-based settings: Lessons learned. *Journal of the American Medical Informatics Association*, 18(6), 749-753.

Implementing health information technology (IT) at the community level is a national priority to help improve healthcare quality, safety, and efficiency. However, community-based organizations implementing health IT may not have expertise in evaluation. This study describes lessons learned from experience as a multi-institutional academic collaborative established to provide independent evaluation of community-based health IT initiatives. The authors' experience derived from adapting the principles of community-based participatory research to the field of health IT. To

assist other researchers, the lessons learned under four themes are presented: (A) the structure of the partnership between academic investigators and the community; (B) communication issues; (C) the relationship between implementation timing and evaluation studies; and (D) study methodology. These lessons represent practical recommendations for researchers interested in pursuing similar collaborations.

Khan, S. A., Ancker, J. S., Li, J., Kaufman, D., Hutchinson, C., Cohall, A., & Kukafka, R. (2009).

GetHealthyHarlem.org: Developing a web platform for health promotion and wellness driven by and for the Harlem community. *AMIA ...Annual Symposium Proceedings/AMIA Symposium, 2009*, 317-321.

GetHealthyHarlem.org is a community website developed on an open-source platform to facilitate collaborative development of health content through participatory action research (PAR) principles. The website was developed to enable the Harlem community to create a shared health and wellness knowledgebase, to enable discourse about local and culturally relevant health information, and to foster social connections between community members and health promotion organizations. The site is gaining active use with more than 9,500 unique site visits in the six months since going live in November, 2008. In ongoing research studies, we are using the website to explore how the PAR model can be applied to the development of a community health website.

Kirsch, I., Jungeblut, A., Jenkins, L. & Kolstad, A. (1993). *Adult literacy in America: A first look at the findings of the National Adult Literacy Survey*. Retrieved April 22 from

<http://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=93275>

This report provides a first look at the results of the National Adult Literacy Survey, a project funded by the U.S. Department of Education's National Center for Education Statistics and administered by Educational Testing Service, in collaboration with Westat, Inc. It provides the most detailed portrait that has ever been available on the condition of literacy in this nation -- and on the unrealized potential of its citizens.

Kupchunas, W. R. (2007). Personal health record: New opportunity for patient education.

Orthopaedic Nursing / National Association of Orthopaedic Nurses, 26(3), 185-91.

doi:10.1097/01.NOR.0000276971.86937.c4

The personal health record (PHR) allows individuals to keep track of their health care information in one location. Maintaining a PHR encourages increased personal participation in healthcare and fosters a greater emphasis on communication between the individual and the caregivers. The creation of a PHR provides the opportunity for health professionals to educate patients about personal health matters and presents a tool for enhancing health literacy. As patients become more adept at communicating with their caregivers and recording important health information, the ability to participate in decision making is enhanced. Assessment of health literacy and functional ability allows the PHR to be adapted to accommodate the needs of the individual. Identification of family members or other significant individuals early on is essential, and education efforts should begin promptly. This article provides information on the benefits of a PHR. Considerations for health literacy and ability to maintain a PHR are discussed, and examples of using a transdisciplinary approach to

development and implementation of a PHR are examined. With proper design and education, the PHR allows individuals to participate more fully in their own healthcare.

Lipkus, I. M. (2007). Numeric, verbal, and visual formats of conveying health risks:

Suggested best practices and future recommendations. *Medical Decision Making*, 27(5), 696-713.

Perception of health risk can affect medical decisions and health behavior change. Yet the concept of risk is a difficult one for the public to grasp. Whether perceptions of risk affect decisions and behaviors often relies on how messages of risk magnitudes (i.e., likelihood) are conveyed. Based on expert opinion, this article offers, when possible, best practices for conveying magnitude of health risks using numeric, verbal, and visual formats. This expert opinion is based on existing empirical evidence, review of papers and books, and consultations with experts in risk communication. This article also discusses formats to use pertaining to unique risk communication challenges (e.g., conveying small-probability events, interactions). Several recommendations are suggested for enhancing precision in perception of risk by presenting risk magnitudes numerically and visually. Overall, there are little data to suggest best practices for verbal communication of risk magnitudes. Across the 3 formats, few overall recommendations could be suggested because of 1) lack of consistency in testing formats using the same outcomes in the domain of interest, 2) lack of critical tests using randomized controlled studies pitting formats against one another, and 3) lack of theoretical progress detailing and testing mechanisms why one format should be more efficacious in a specific context to affect risk magnitudes than others. Areas of future

research are provided that it is hoped will help illuminate future best practices.

[References: 158]

Lipkus, I. M., & Peters, E. (2009). Understanding the role of numeracy in health: Proposed theoretical framework and practical insights. *Health Education & Behavior, 36*(6), 1065-1081.

Numeracy-that is, how facile people are with mathematical concepts and their applications-is gaining importance in medical decision making and risk communication. This article proposes six critical functions of health numeracy. These functions are integrated into a theoretical framework on health numeracy that has implications for risk communication and medical decision-making processes. The authors examine practical underpinnings for targeted interventions aimed at improving such processes as a function of health numeracy. They hope that the proposed functions and theoretical framework will spur more research to determine how an understanding of health numeracy can lead to more effective communication and decision outcomes.

Lipkus, I. M., Samsa, G., & Rimer, B. K. (2001). General performance on a numeracy scale among highly educated samples. *Medical Decision Making, 21*(1), 37-44.

BACKGROUND: Numeracy, how facile people are with basic probability and mathematical concepts, is associated with how people perceive health risks.

Performance on simple numeracy problems has been poor among populations with little as well as more formal education. Here, we examine how highly educated participants performed on a general and an expanded numeracy scale. The latter was

designed within the context of health risks. METHOD: A total of 463 men and women aged 40 and older completed a 3-item general and an expanded 7-item numeracy scale. The expanded scale assessed how well people 1) differentiate and perform simple mathematical operations on risk magnitudes using percentages and proportions, 2) convert percentages to proportions, 3) convert proportions to percentages, and 4) convert probabilities to proportions. RESULTS: On average, 18% and 32% of participants correctly answered all of the general and expanded numeracy scale items, respectively. Approximately 16% to 20% incorrectly answered the most straightforward questions pertaining to risk magnitudes (e.g., Which represents the larger risk: 1%, 5%, or 10%?). A factor analysis revealed that the general and expanded risk numeracy items tapped the construct of global numeracy. CONCLUSIONS: These results suggest that even highly educated participants have difficulty with relatively simple numeracy questions, thus replicating in part earlier studies. The implication is that usual strategies for communicating numerical risk may be flawed. Methods and consequences of communicating health risk information tailored to a person's level of numeracy should be explored further.

MLA (Medical Library Association). (2011). *A user's guide to finding and evaluating health information on the web*. Retrieved December 26, 2011, from <http://www.mlanet.org/resources/userguide.html>

This guide outlines the collective wisdom of medical librarians who surf the web every day to discover quality information in support of clinical and scientific decision making by doctors, scientists, and other health practitioners responsible for the nation's health. This guide is supported by the Medical Library Association (MLA), the library

organization whose primary purpose is promoting quality information for improved health and whose members were the first to realize that not all health information on the web is credible, timely, or safe.

The guide is presented in three brief sections. The first section, "Getting Started," provides tips on filtering the millions of health-related web pages through the health subsets of major search engines and using quality electronic finding tools developed by the U.S. government to do an initial screen of websites for further examination. This section is followed by a set of guidelines developed for evaluating the content of health-related websites. The final section provides additional information of interest to consumers searching for health-related information on the web.

National Network of Libraries of Medicine. (2011). *Health literacy*. Retrieved December 26, 2011, from <http://nnlm.gov/outreach/consumer/hlthlit.html>

Excellent high level reference of health literacy. Many links to other resources

Oldfield, S. R., & Dreher, H. M. (2010). The concept of health literacy within the older adult population. *Holistic Nursing Practice*, 24(4), 204-212.

Health literacy is a relatively new concept that has been evolving at a rapid pace over the past decade. As recently as 2004, nursing researchers were contributing only a small portion of the existing body of knowledge as it related to the concept of health literacy. But in the last 4 to 5 years, this trend has changed. More interest demonstrated by nursing scholars has caused an exponential increase in the literature being produced. The research to date has shown a direct correlation between low health literacy and poor health. Older adults have been identified as a vulnerable

population with an estimated two-thirds of US adults aged 60 and older having inadequate or marginal literacy skills. A concept analysis of health literacy in the older adult population is warranted at this time to further clarify the concept and provide standard terminology and definitions for future holistic nursing practice and research, leading to better identification of health-literacy deficits and intervention within vulnerable populations. [References: 62]

Osborn, C. Y., Cavanaugh, K., Wallston, K. A., White, R. O., & Rothman, R. L. (2009). Diabetes numeracy: An overlooked factor in understanding racial disparities in glycemic control. *Diabetes Care*, 32(9), 1614-1619.

OBJECTIVE: Understanding the reasons and eliminating the pervasive health disparities in diabetes is a major research, clinical, and health policy goal. We examined whether health literacy, general numeracy, and diabetes-related numeracy explain the association between African American race and poor glycemic control (A1C) in patients with diabetes. RESEARCH DESIGN AND METHODS: Adults with type 2 diabetes (n = 383) were enrolled in a cross-sectional study at primary care and diabetes clinics at three medical centers. Data collected included the following: self-reported race, health literacy, general numeracy, diabetes-related numeracy, A1C, and sociodemographic factors. A series of structural equation models were estimated to explore the interrelations between variables and test for mediation. RESULTS: In model 1, younger age ($r = -0.21, P < 0.001$), insulin use ($r = 0.27, P < 0.001$), greater years with diabetes ($r = 0.16, P < 0.01$), and African American race ($r = 0.12, P < 0.01$) were all associated with poorer glycemic control. In model 2, diabetes-related numeracy emerged as a strong predictor of A1C ($r = -0.46, P < 0.001$), reducing the

association between African American and poor glycemic control to nonsignificance ($r = 0.10$, NS). In model 3, African American race and older age were associated with lower diabetes-related numeracy; younger age, insulin use, more years with diabetes, and lower diabetes-related numeracy were associated with poor glycemic control. CONCLUSIONS: Diabetes-related numeracy reduced the explanatory power of African American race, such that low diabetes-related numeracy, not African American race, was significantly related to poor glycemic control. Interventions that address numeracy could help to reduce racial disparities in diabetes.

Parker, R. M., Baker, D. W., Williams, M. V., & Nurss, J. R. (1995). The test of functional health literacy in adults: A new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine, 10*(10), 537-541.

OBJECTIVE: To develop a valid, reliable instrument to measure the functional health literacy of patients. DESIGN: The Test of Functional Health Literacy in Adults (TOFHLA) was developed using actual hospital materials. The TOFHLA consists of a 50-item reading comprehension and 17-item numerical ability test, taking up to 22 minutes to administer. The TOFHLA, the Wide Range Achievement Test--Revised (WRAT-R), and the Rapid Estimate of Adult Literacy in Medicine (REALM) were administered for comparison. A Spanish version was also developed (TOFHLA-S). SETTING: Outpatient settings in two public teaching hospitals. PATIENTS: 256 English- and 249 Spanish-speaking patients were approached. 78% of the English- and 82% of the Spanish-speaking patients gave informed consent, completed a demographic survey, and took the TOFHLA or TOFHLA-S. RESULTS: The TOFHLA showed good correlation with the WRAT-R and the REALM (correlation coefficients 0.74 and 0.84,

respectively). Only 52% of the English speakers completed more than 80% of the questions correctly. 15% of the patients could not read and interpret a prescription bottle with instructions to take one pill by mouth four times daily, 37% did not understand instructions to take a medication on an empty stomach, and 48% could not determine whether they were eligible for free care. CONCLUSIONS: The TOFHLA is a valid, reliable indicator of patient ability to read health-related materials. Data suggest that a high proportion of patients cannot perform basic reading tasks. Additional work is needed to determine the prevalence of functional health illiteracy and its effect on the health care experience.

Peters, E., Dieckmann, N., Dixon, A., Hibbard, J. H., & Mertz, C. K. (2007). Less is more in presenting quality information to consumers. *Medical Care Research & Review*, 64(2), 169-190.

Much effort has been put into improving measures of health care quality. Although early research suggested that consumers made little use of quality reports, most reports were based on nonstandardized measures and were not user friendly. Information presentation approaches, however, will have a significant influence on what information is attended and used. The present research examines whether information presentation methods differentially influence consumers who differ in numeric skills. Results of three studies support the idea that “less is more” when presenting consumers with comparative performance information to make hospital choices. Results were particularly strong for those lower in numeracy, who had higher comprehension and made better choices when the information-presentation format was designed to ease the cognitive burden and highlight the meaning of important

information. These findings have important implications for the sponsors of comparative quality reports designed to inform consumer decision making in health care.

Powers, B. J., Trinh, J. V., & Bosworth, H. B. (2010). Can this patient read and understand written health information? *JAMA*, *304*(1), 76-84.

CONTEXT: Patients with limited literacy are at higher risk for poor health outcomes; however, physicians' perceptions are inaccurate for identifying these patients.

OBJECTIVE: To systematically review the accuracy of brief instruments for identifying patients with limited literacy. DATA SOURCES: Search of the English-language literature from 1969 through February 2010 using PubMed, Psycinfo, and bibliographies of selected manuscripts for articles on health literacy, numeracy, reading ability, and reading skill. STUDY SELECTION: Prospective studies including adult patients 18 years or older that evaluated a brief instrument for identifying limited literacy in a health care setting compared with an accepted literacy reference standard. DATA EXTRACTION: Studies were evaluated independently by 2 reviewers who each abstracted information and assigned an overall quality rating.

Disagreements were adjudicated by a third reviewer. DATA SYNTHESIS: Ten studies using 6 different instruments met inclusion criteria. Among multi-item measures, the Newest Vital Sign (English) performed moderately well for identifying limited literacy based on 3 studies. Among the single-item questions, asking about a patient's use of a surrogate reader, confidence filling out medical forms, and self-rated reading ability performed moderately well in identifying patients with inadequate or marginal literacy. Asking a patient, "How confident are you in filling out medical forms by

yourself?" is associated with a summary likelihood ratio (LR) for limited literacy of 5.0 (95% confidence interval [CI], 3.8-6.4) for an answer of "a little confident" or "not at all confident"; a summary LR of 2.2 (95% CI, 1.5-3.3) for "somewhat confident"; and a summary LR of 0.44 (95% CI, 0.24-0.82) for "quite a bit" or "extremely confident."

CONCLUSION: Several single-item questions, including use of a surrogate reader and confidence with medical forms, were moderately effective for quickly identifying patients with limited literacy. [References: 46]

Rothman, R. L., Housam, R., Weiss, H., Davis, D., Gregory, R., Gebretsadik, T., . . . Elasy, T. A. (2006). Patient understanding of food labels: The role of literacy and numeracy. *American Journal of Preventive Medicine, 31*(5), 391-398.

BACKGROUND: Comprehension of food labels can be important for patients, including those with chronic illness, to help follow dietary recommendations. Patient comprehension of food labels was examined, along with the relationship of comprehension to their underlying literacy and numeracy skills. METHODS: From June 2004 to April 2005, a cross-sectional study of 200 primary care patients was performed. A 24-item measure of food label comprehension was administered. Literacy was measured with the Rapid Estimate of Adult Literacy in Medicine (REALM), and numeracy with the Wide Range Achievement Test, third edition (WRAT-3). RESULTS: Most patients (89%) reported using food labels. While 75% of patients reported at least a high school education and 77% had 9th-grade literacy skills, only 37% had 9th-grade math skills. On average, patients answered 69% (standard deviation, 21%) of the food-label questions correctly. Common reasons for incorrect responses included misapplication of the serving size, confusion due to extraneous

material on the food label, and incorrect calculations. For example, only 37% of patients could calculate the number of carbohydrates consumed from a 20-ounce bottle of soda that contained 2.5 servings. Higher comprehension of food labels was significantly correlated (all p values were less than 0.001) with higher income ($\rho=0.39$), education ($\rho=0.49$), literacy ($\rho=0.52$), and numeracy ($\rho=0.67$).

CONCLUSIONS: Patients demonstrated deficits in understanding nutrition labels. Poor label comprehension was highly correlated with low-level literacy and numeracy skills, but even patients with higher literacy could have difficulties interpreting labels. Providers need to consider patients' literacy and numeracy when providing dietary recommendations. Opportunities may exist for the U.S. Food and Drug Administration to promote changes to make food labels more comprehensible.

Schapira, M. M., Fletcher, K. E., Gilligan, M. A., King, T. K., Laud, P. W., Matthews, B. A., . . .

Hayes, E. (2008). A framework for health numeracy: How patients use quantitative skills in health care. *Journal of Health Communication, 13*(5), 501-517.

Our objective of this study is to develop a conceptual framework for the construct of health numeracy based on patient perceptions, using a cross-sectional, qualitative design. Interested participants (n=59) meeting eligibility criteria (age 40-74, English speaking) were assigned to one of six focus groups stratified by gender and educational level (low, medium, high). Fifty-three percent were male, and 47% were female. Sixty-one percent were white non-Hispanic, and 39% were of minority race or ethnicity. Participants were randomly selected from three primary care sites associated with an academic medical center. Focus group discussions were held in May 2004 and focused on how numbers are used in the health care setting. Data were

presented from clinical trials to further explore how quantitative information is used in health communication and decision making. Focus groups were audio and videotaped; verbatim transcripts were prepared and analyzed. A framework of health numeracy was developed to reflect the themes that emerged. Three broad conceptual domains for health numeracy were identified: primary numeric skills, applied health numeracy, and interpretive health numeracy. Across domains, results suggested that numeracy contains an emotional component, with both positive and negative affect reflected in patient numeracy statements. We conclude that health numeracy is a multifaceted construct that includes applied and interpretive components and is influenced by patient affect.

Schwartz, L. M., Woloshin, S., Black, W. C., & Welch, H. G. (1997). The role of numeracy in understanding the benefit of screening mammography. *Annals of Internal Medicine*, 127(11), 966-972.

BACKGROUND: Quantitative information about risks and benefits may be meaningful only to patients who have some facility with basic probability and numerical concepts, a construct called numeracy. **OBJECTIVE:** To assess the relation between numeracy and the ability to make use of typical risk reduction expressions about the benefit of screening mammography. **DESIGN:** Randomized, cross-sectional survey. **SETTING:** A simple random sample of 500 female veterans drawn from a New England registry. **INTERVENTION:** One of four questionnaires, which differed only in how the same information on average risk reduction with mammography was presented.

MEASUREMENTS: Numeracy was scored as the total number of correct responses to three simple tasks. Participants estimated their risk for death from breast cancer with

and without mammography. Accuracy was judged as each woman's ability to adjust her perceived risk in accordance with the risk reduction data presented. RESULTS: 61% of eligible women completed the questionnaire. The median age of these women was 68 years (range, 27 to 88 years), and 96% were high school graduates. Both accuracy in applying risk reduction information and numeracy were poor (one third of respondents thought that 1000 flips of a fair coin would result in < 300 heads).

Accuracy was strongly related to numeracy: The accuracy rate was 5.8% (95% CI, 0.8% to 10.7%) for a numeracy score of 0, 8.9% (CI, 2.5% to 15.3%) for a score of 1, 23.7% (CI, 13.9% to 33.5%) for a score of 2, and 40% (CI, 25.1% to 54.9%) for a score of 3. CONCLUSIONS: Regardless of how information was presented, numeracy was strongly related to accurately gauging the benefit of mammography. More effective formats are needed to communicate quantitative information about risks and benefits.

Schwartz, L. M., Woloshin, S., & Welch, H. G. (2005). Can patients interpret health information? An assessment of the medical data interpretation test. *Medical Decision Making, 25*(3), 290-300.

OBJECTIVE: To establish the reliability/validity of an 18-item test of patients' medical data interpretation skills. DESIGN: Survey with retest after 2 weeks. Subjects. 178 people recruited from advertisements in local newspapers, an outpatient clinic, and a hospital open house. RESULTS: The percentage of correct answers to individual items ranged from 20% to 87%, and medical data interpretation test scores (on a 0- 100 scale) were normally distributed (median 61.1, mean 61.0, range 6-94). Reliability was good (test-retest correlation=0.67, Cronbach's alpha=0.71). Construct validity was supported in several ways. Higher scores were found among people with highest

versus lowest numeracy (71 v. 36, $P < 0.001$), highest quantitative literacy (65 v. 28, $P < 0.001$), and highest education (69 v. 42, $P = 0.004$). Scores for 15 physician experts also completing the survey were significantly higher than participants with other postgraduate degrees (mean score 89 v. 69, $P < 0.001$). CONCLUSION: The medical data interpretation test is a reliable and valid measure of the ability to interpret medical statistics.

Shaw, S. J., Huebner, C., Armin, J., Orzech, K., & Vivian, J. (2009). The role of culture in health literacy and chronic disease screening and management. *Journal of Immigrant & Minority Health, 11*(6), 460-467.

Cultural and language differences and socioeconomic status interact with and contribute to low health literacy, defined as the inability to understand or act on medical/therapeutic instructions. Health literacy is increasingly recognized as an important factor in patient compliance, cancer screening utilization, and chronic disease outcomes. Commendable efforts have been initiated by the American Medical Association and other organizations to address low health literacy among patients. Less work has been done, however, to place health literacy in the broader context of socioeconomic and cultural differences among patients and providers that hinder communication and compliance. This review examines cultural influences on health literacy, cancer screening and chronic disease outcomes. We argue that cultural beliefs around health and illness contribute to an individual's ability to understand and act on a health care provider's instructions. This paper proposes key aspects of the intersection between health literacy and culturally varying beliefs about health which merit further exploration. [References: 86]

Smith, C. A. (2011). Consumer language, patient language, and thesauri: A review of the literature. *Journal of the Medical Library Association*, 99(2), 135-144.

OBJECTIVE: Online social networking sites are web services in which users create public or semipublic profiles and connect to build online communities, finding like-minded people through self-labeled personal attributes including ethnicity, leisure interests, political beliefs, and, increasingly, health status. Thirty-nine percent of patients in the United States identified themselves as users of social networks in a recent survey. "Tags," user-generated descriptors functioning as labels for user-generated content, are increasingly important to social networking, and the language used by patients is thus becoming important for knowledge representation in these systems. However, patient language poses considerable challenges for health communication and networking. How have information systems traditionally incorporated these languages in their controlled vocabularies and thesauri? How do system builders know what consumers and patients say? **METHODS:** This comprehensive review of the literature of health care (PubMed MEDLINE, CINAHL), library science, and information science (Library and Information Science and Technology Abstracts, Library and Information Science Abstracts, and Library Literature) examines the research domains in which consumer and patient language has been explored. **RESULTS:** Consumer contributions to controlled vocabulary appear to be seriously under-researched inside and outside of health care. **CONCLUSION:** The author reflects on the implications of these findings for online social networks devoted to patients and the patient experience.

Smith, S., & Duman, M. (2009). The state of consumer health information: An overview. *Health Information & Libraries Journal*, 26(4), 260-278.

BACKGROUND: Consumer health information is becoming increasingly important and health policy in the UK is beginning to reflect this. This has implications for information producers, providers and users, with the move towards a more patient-centred health service. OBJECTIVES: This review aims to provide a broad overview of the current state of consumer health information in the UK. It examines the changing roles of information producers, providers and users, exploring the impact of health literacy and new technologies. It features some of the current library and consumer health information projects taking place in the UK and discusses the role that libraries may play in the future. METHODS: The article focuses on consumer health information in a policy context. It is based on the experiences of the authors' work for the Patient Information Forum and knowledge of consumer health information. A number of library and information professionals were consulted regarding the library and information projects. CONCLUSIONS: Communication between health professionals and patients, and between health educators and the public, is key in order for consumer health information to have the ability to improve health outcomes. Further, especially local, investment into the production, distribution and delivery of consumer health information is recommended. [References: 59]

Tait, A. R., Zikmund-Fisher, B. J., Fagerlin, A., & Voepel-Lewis, T. (2010). Effect of various risk/benefit trade-offs on parents' understanding of a pediatric research study. *Pediatrics*, 125(6), e1475-82.

OBJECTIVES: Informed decision-making requires that parents and research subjects understand the risks and benefits of a study, yet research suggests that comprehension of these elements is often poor. This study was designed to examine the effect of factors including manipulation of risk/benefit trade-offs, numeracy, and sociodemographics on parents' understanding of risks and benefits.

METHODS: A total of 4685 parents completed an Internet survey in which they were randomly assigned to receive information about the risks and benefits of a hypothetical pain treatment study presented in 1 of 4 scenarios. Parents' gist (essential) and verbatim (exact) understanding and their perceptions of the risks and benefits were compared across scenarios. The effects of parental sociodemographics and numeracy were also examined.

RESULTS: Participants who were randomly assigned to consider a research study that offered the possibility of improved outcomes had higher gist and verbatim understanding of the information than participants who were considering studies that offered only reductions in the risk for adverse effects. Furthermore, these parents perceived the risks of the study to be significantly lower compared with the scenarios that offered the same risks but less benefit. White race, college education, and higher numeracy all were associated significantly with improved gist and verbatim understanding.

CONCLUSIONS: Research studies that offer only improved outcomes to participants may be evaluated more thoroughly than those that offer only reduced risks, and individual characteristics significantly moderate parents' ability to comprehend risk/benefit information. These results are important toward developing strategies to

improve the ways in which risks and benefits are communicated to parents and research subjects.

U.S. Department of Health and Human Services. (2012). *Healthy People 2020, Health communication and health information technology objectives*. Retrieved January 8, 2012, from <http://www.healthypeople.gov/2020/topicsobjectives2020/objectiveslist.aspx?topicid=18>.

Goal

Use health communication strategies and health information technology (IT) to improve population health outcomes and health care quality, and to achieve health equity.

Overview

Ideas about health and behaviors are shaped by the communication, information, and technology that people interact with every day. Health communication and health information technology (IT) are central to health care, public health, and the way our society views health. These processes make up the context and the ways professionals and the public search for, understand, and use health information, significantly impacting their health decisions and actions.

The objectives in this topic area describe many ways health communication and health IT can have a positive impact on health, health care, and health equity. The objectives are listed along with details for each one

US Department of Health and Human Services, Office of Disease Prevention and Health

Promotion. (2010). *National Action Plan to Improve Health Literacy*. Retrieved January 7 from <http://www.health.gov/communication/hlactionplan/>

This *National Action Plan to Improve Health Literacy* seeks to engage organizations, professionals, policymakers, communities, individuals, and families in a linked, multisector effort to improve health literacy. The plan is based on the principles that (1) everyone has the right to health information that helps them make informed decisions and (2) health services should be delivered in ways that are understandable and beneficial to health, longevity, and quality of life. The vision informing this plan is of a society that: Provides everyone with access to accurate and actionable health information, Delivers person-centered health information and services, and Supports lifelong learning and skills to promote good health.

Weiss, B. D., Mays, M. Z., Martz, W., Castro, K. M., DeWalt, D. A., Pignone, M. P., . . . Hale, F. A. (2005). Quick assessment of literacy in primary care: The newest vital sign. *Annals of Family Medicine*, 3(6), 514-522.

PURPOSE: Current health literacy screening instruments for health care settings are either too long for routine use or available only in English. Our objective was to develop a quick and accurate screening test for limited literacy available in English and Spanish. METHODS: We administered candidate items for the new instrument and also the Test of Functional Health Literacy in Adults (TOFHLA) to English-speaking and Spanish-speaking primary care patients. We measured internal consistency with Cronbach's alpha and assessed criterion validity by measuring correlations with TOFHLA scores. Using TOFHLA scores 0.76 in English and 0.69 in Spanish) and

correlates with the TOFHLA. Area under the ROC curve is 0.88 for English and 0.72 for Spanish versions. Patients with more than 4 correct responses are unlikely to have low literacy, whereas fewer than 4 correct answers indicate the possibility of limited literacy. CONCLUSION: NVS is suitable for use as a quick screening test for limited literacy in primary health care settings.

Wharf Higgins, J., Begoray, D., & MacDonald, M. (2009). A social ecological conceptual framework for understanding adolescent health literacy in the health education classroom. *American Journal of Community Psychology, 44*(3-4), 350-362.

With the rising concern over chronic health conditions and their prevention and management, health literacy is emerging as an important public health issue. As with the development of other forms of literacy, the ability for students to be able to access, understand, evaluate and communicate health information is a skill best developed during their years of public schooling. Health education curricula offer one approach to develop health literacy, yet little is known about its influence on neither students nor their experiences within an educational context. In this article, we describe our experience applying a social ecological model to investigating the implementation of a health education curriculum in four high schools in British Columbia, Canada. We used the model to guide a conceptual understanding of health literacy, develop research questions, select data collection strategies, and interpret the findings. Reflections and recommendations for using the model are offered. [References: 47]

Wolf, M. S., & Bailey, S. C. (2009). *The role of health literacy in patient safety*. Retrieved April 22 from <http://webmm.ahrq.gov/perspective.aspx?perspectiveID=72>

Strategies to promote health literacy by helping patients more easily obtain, process, and understand health information to be able to make informed decisions ultimately supports patient safety. The health system must promote better communication of health information while also simplifying the demands it places on patients. However, patients and families must also recognize their roles and responsibilities to be informed and vigilant in protecting their health. A safer health care environment can only be achieved if patients are included as active participants and health care providers and systems clearly communicate their expectations.

Woloshin, S., Schwartz, L. M., Moncur, M., Gabriel, S., & Tosteson, A. N. (2001). Assessing values for health: Numeracy matters. *Medical Decision Making*, 21(5), 382-390.

BACKGROUND: Patients' values are fundamental to decision models, cost-effectiveness analyses, and pharmacoeconomic analyses. The standard methods used to assess how patients value different health states are inherently quantitative. People without strong quantitative skills (i.e., low numeracy) may not be able to complete these tasks in a meaningful way. METHODS: To determine whether the validity of utility assessments depends on the respondent's level of numeracy, the authors conducted in-person interviews and written surveys and assessed utility for the current health for 96 women volunteers. Numeracy was measured using a previously validated 3-item scale. The authors examined the correlation between self-reported health and utility for current health (assessed using the standard gamble, time trade-off, and visual analog techniques) across levels of numeracy. For half of the women, the authors also assessed standard gamble utility for 3 imagined health states (breast cancer, heart disease, and osteoporosis) and asked how much the women feared each disease.

RESULTS: Respondent ages ranged from 50 to 79 years (mean = 63), all were high school graduates, and 52% had a college or postgraduate degree. Twenty-six percent answered 0 or only 1 of the numeracy questions correctly, 37% answered 2 correctly, and 37% answered all 3 correctly. Among women with the lowest level of numeracy, the correlation between utility for current health and self-reported health was in the wrong direction (i.e., worse health valued higher than better health): for standard gamble, Spearman $r=-0.16$, $P = 0.44$; for time trade-off, Spearman $r=-0.13$, $P=0.54$. Among the most numerate women, the authors observed a fair to moderate positive correlation with both standard gamble (Spearman $r=0.22$, $P=0.19$) and time trade-off (Spearman $r=0.50$, $P=0.002$). In contrast, using the visual analog scale, the authors observed a substantial correlation in the expected direction at all levels of numeracy (Spearman $r= 0.82$, 0.50 , and 0.60 for women answering 0-1, 2, and 3 numeracy questions, respectively; all P s $< \text{or} = 0.003$). With regard to the imagined health states, the most feared disease had the lowest utility for 35% of the women with the lowest numeracy compared to 76% of the women with the highest numeracy ($P=0.03$).

CONCLUSIONS: The validity of standard utility assessments is related to the subject's facility with numbers. Limited numeracy may be an important barrier to meaningfully assessing patients' values using the standard gamble and time trade-off techniques.

Wuerdeman, L., Volk, L., Pizziferri, L., Tsurikova, R., Harris, C., Feygin, R., . . . Bates, D. W. (2005). How accurate is information that patients contribute to their Electronic Health Record? *AMIA ...Annual Symposium Proceedings / AMIA Symposium. AMIA Symposium*, , 834-838.

Increased patient interaction with medical records and the advent of personal health

records (PHRs) may increase patients' ability to contribute valid information to their Electronic Medical Record (EHR) medical record. Patient input through a secure connection, whether it be a patient portal or PHR, will integrate many aspects of a patient's health and may help lessen the information gap between patients and providers. Patient reported data should be considered a viable method of enhancing documentation but will not likely be as complete and accurate as more comprehensive data-exchange between providers.

Zamora, H., & Clingerman, E. M. (2011). Health literacy among older adults: A systematic literature review. *Journal of Gerontological Nursing*, 37(10), 41-51.

The purpose of this systematic literature review was to describe the empirical findings on health literacy in adults 65 and older. A systematic search for research studies from 1999 to early 2010 was conducted in MEDLINE and CINAHL databases. Articles were analyzed using the following foci: skills and health knowledge, functional health literacy, and health behaviors and health outcomes. Findings indicated that advancing age resulted in a significant increase in prevalence of inadequate health literacy.

Further research is needed to develop evidence-based, culturally congruent interventions to improve health literacy among older adults. Copyright 2011, SLACK Incorporated.

Measures – Annotated Bibliography

Kim, E. H., Stolyar, A., Lober, W. B., Herbaugh, A. L., Shinstrom, S. E., Zierler, B. K., . . . Kim, Y. (2007). Usage patterns of a personal health record by elderly and disabled users. *AMIA Annual Symposium Proceedings, 2007*, 409-413.

Personal Health Records (PHRs) are increasingly recognized as a strategy to improve patient-provider communication, availability of health information, and quality of care, by making the delivery of care more patient-centered. However, not much is known about the effects of self-managing personal health information (PeHI), patients' perception of PeHI and patient workflow around PeHI management. We studied PHR use in a low-income, elderly and/or disabled population for 18 months, and describe how the PHR was used through an analysis of database access server log data. Some patients may not keep their PHR up-to-date because they don't value, can't access, or don't understand certain categories of their health information. Understanding of usage patterns can guide the development and maintenance of more usable and pragmatic PHR systems.

Markle Foundation. *Markle Study on Health in a Networked Life 2010*. Retrieved April 22, 2011, from <http://www.markle.org/health/health-networked-life>

Health in a Networked Life is an exploration of the social and cultural changes attributed to an increasingly interconnected and electronically tracked society. The Markle Survey of Health in a Networked Life directly examines physician and consumer expectations at the outset of federal health IT stimulus and health care reform.

Wagner, P. J., Dias, J., Howard, S., Kintziger, K. W., Hudson, M. F., Seol, Y. H., & Sodomka, P.

(2012). Personal health records and hypertension control: A randomized trial. *Journal of the American Medical Informatics Association*, 2012 Jan 12, Epub ahead of print.

doi:10.1136/amiajnl-2011-000349

Purpose: To examine the impact of a personal health record (PHR) in patients with hypertension measured by changes in biological outcomes, patient empowerment, patient perception of quality of care, and use of medical services. **Methods** A cluster-randomized effectiveness trial with PHR and no PHR groups was conducted in two ambulatory clinics. 453 of 1686 (26.4%) patients approached were included in the analyses. A PHR tethered to the patient's electronic medical record (EMR) was the primary intervention and included security measures, patient control of access, limited transmission of EMR data, blood pressure (BP) tracking, and appointment assistance. BP was the main outcome measure. Patient empowerment was assessed using the Patient Activation Measure and Patient Empowerment Scale. Quality of care was assessed using the Clinician and Group Assessment Score (CAHPS) and the Patient Assessment of Chronic Illness Care. Frequency of use of medical services was self-reported. **Results** No impact of the PHR was observed on BP, patient activation, patient perceived quality, or medical utilization in the intention-to-treat analysis. Sub-analysis of intervention patients self-identified as active PHR users (25.7% of those with available information) showed a 5.25-point reduction in diastolic BP. Younger age, self-reported computer skills, and more positive provider communication ratings were associated with frequency of PHR use. **Conclusions** Few patients provided with a PHR actually used the PHR with any frequency. Thus simply providing a PHR may have

limited impact on patient BP, empowerment, satisfaction with care, or use of health services without additional education or clinical intervention designed to increase PHR use. Clinical trial registration number <http://ClinicalTrials.gov> Identifier: NCT01317537.

Wright, A., Poon, E. G., Wald, J., Feblowitz, J., Pang, J. E., Schnipper, J. L., . . . Middleton, B.

(2012). Randomized controlled trial of health maintenance reminders provided directly to patients through an electronic PHR. *Journal of General Internal Medicine*, 27(1), 85-92. doi:10.1007/s11606-011-1859-6

BACKGROUND: Provider and patient reminders can be effective in increasing rates of preventive screenings and vaccinations. However, the effect of patient-directed electronic reminders is understudied. **OBJECTIVE:** To determine whether providing reminders directly to patients via an electronic Personal Health Record (PHR) improved adherence to care recommendations. **DESIGN:** We conducted a cluster randomized trial without blinding from 2005 to 2007 at 11 primary care practices in the Partners HealthCare system. **PARTICIPANTS:** A total of 21,533 patients with access to a PHR were invited to the study, and 3,979 (18.5%) consented to enroll.

INTERVENTIONS: Patients in the intervention arm received health maintenance (HM) reminders via a secure PHR "eJournal," which allowed them to review and update HM and family history information. Patients in the active control arm received access to an eJournal that allowed them to input and review information related to medications, allergies and diabetes management. **MAIN MEASURES:** The primary outcome measure was adherence to guideline-based care recommendations. **KEY RESULTS:** Intention-to-treat analysis showed that patients in the intervention arm were significantly more

likely to receive mammography (48.6% vs 29.5%, $p = 0.006$) and influenza vaccinations (22.0% vs 14.0%, $p = 0.018$). No significant improvement was observed in rates of other screenings. Although Pap smear completion rates were higher in the intervention arm (41.0% vs 10.4%, $p < 0.001$), this finding was no longer significant after excluding women's health clinics. Additional on-treatment analysis showed significant increases in mammography ($p = 0.019$) and influenza vaccination ($p = 0.015$) for intervention arm patients who opened an eJournal compared to control arm patients, but no differences for any measure among patients who did not open an eJournal. CONCLUSIONS: Providing patients with HM reminders via a PHR may be effective in improving some elements of preventive care.

Zulman, D. M., Nazi, K. M., Turvey, C. L., Wagner, T. H., Woods, S. S., & An, L. C. (2011).

Patient interest in sharing personal health record information: A web-based survey. *Annals of Internal Medicine*, 155(12), 805-810. doi:10.1059/0003-4819-155-12-201112200-00002

BACKGROUND: Electronic personal health record (PHR) systems are proliferating but largely have not realized their potential for enhancing communication among patients and their network of care providers. OBJECTIVE: To explore preferences about sharing electronic health information among users of the U.S. Department of Veterans Affairs (VA) PHR system, My HealtheVet. DESIGN: Web-based survey of a convenience sample. SETTING: My HealtheVet Web site from 7 July through 4 October 2010.

PARTICIPANTS: 18 471 users of My HealtheVet. MEASUREMENTS: Interest in shared PHR access and preferences about who would receive access, the information that would be shared, and the activities that users would delegate. RESULTS: Survey

respondents were predominantly men (92%) and aged 50 to 64 years (51%) or 65 years or older (39%); approximately 39% reported poor or fair health status. Almost 4 of 5 respondents (79%) were interested in sharing access to their PHR with someone outside of their health system (62% with a spouse or partner, 23% with a child, 15% with another family member, and 25% with a non-VA health care provider). Among those who selected a family member other than a spouse or partner, 47% lived apart from the specified person. Preferences about degree of access varied on the basis of the type of information being shared, the type of activity being performed, and the respondent's relationship with the selected person. LIMITATIONS: The survey completion rate was 40.8%. Results might not be generalizable to all My HealtheVet users. CONCLUSION: In a large survey of PHR users in the VA system, most respondents were interested in sharing access to their electronic health information with caregivers and non-VA providers. Existing and evolving PHR systems should explore secure mechanisms for shared PHR access to improve information exchange among patients and the multiple persons involved in their health care. PRIMARY FUNDING SOURCE: Veterans Health Administration and The Robert Wood Johnson Foundation Clinical Scholars Program.

Privacy and Security – Annotated Bibliography

Allaert, F. A., & Quantin, C. (2010). Patients' empowerment of their personal health record requires strong traceability to guarantee patients health care security. *Studies in Health Technology and Informatics*, 155, 43-47.

Giving patients power over their personal health record is an unavoidable evolution in all industrialized countries which will reflect their active participation in the management of their own health. This would lead to patients sharing management with health professionals, which would need traceability of the data provider to maintain trust and transparency. The systematic use of electronic signatures by medical practitioners will be essential to provide sufficient guarantees and to clearly determine who has added what in the PEHR.

Ball, M. J., Smith, C., & Bakalar, R. S. (2007). Personal health records: empowering consumers. *Journal of Healthcare Information Management*, 21(1), 76-86.

By empowering consumers, electronic personal health records (ePHRs, more commonly PHRs) will play a key role in the evolving electronically enabled health information environment. Consumers want to be more engaged in their own healthcare and are seeking out information online. Despite intense concerns about confidentiality and security, they have high expectations for electronic health information. The growth of patient self-management tools for remote monitoring will fuel PHR adoption, if tools and standards are developed that make clinical information understandable to and usable by consumers. The value of the PHR will lie in shared information and shared decision-making, as its components support the continuity of

care. Efforts in other countries can provide guidance in helping Americans do what they do best-develop and use innovative technology to serve the American people.

Carrion, I., Aleman, J. L., & Toval, A. (2011). Assessing the HIPAA standard in practice: PHR privacy policies. *Conference Proceedings : ...Annual International Conference of the IEEE Engineering in Medicine and Biology Society.IEEE Engineering in Medicine and Biology Society.Conference, 2011*, 2380-2383. doi:10.1109/IEMBS.2011.6090664

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.

Conn, J. (2006). Personal and (maybe) confidential. Questions over privacy, formats and definitions remain, but personal health records are on the way. *Modern Healthcare*, 36(27), 28-31.

Brief report about CMS giving PHRs another huge boost by awarding contracts to two vendors to develop pilot programs to demonstrate how user-friendly PHRs could be

generated from claims data for 42.1 million Medicare beneficiaries. A definition from AHIMA is provided about what is a PHR, and then a several events and vendors who laid the foundation for PHR development are mentioned. Privacy issues are briefly discussed as are standards for PHRs.

Cushman, R., Froomkin, A. M., Cava, A., Abril, P., & Goodman, K. W. (2010). Ethical, legal and social issues for personal health records and applications. *Journal of Biomedical Informatics*, 43(5 Suppl), S51-5. doi:10.1016/j.jbi.2010.05.003

Robert Wood Johnson Foundation's Project HealthDesign included funding of an ethical, legal and social issues (ELSI) team, to serve in an advisory capacity to the nine design projects. In that capacity, the authors had the opportunity to analyze the personal health record (PHR) and personal health application (PHA) implementations for recurring themes. PHRs and PHAs invert the long-standing paradigm of health care institutions as the authoritative data-holders and data-processors in the system. With PHRs and PHAs, the individual is the center of his or her own health data universe, a position that brings new benefits but also entails new responsibilities for patients and other parties in the health information infrastructure. Implications for law, policy and practice follow from this shift. This article summarizes the issues raised by the first phase of Project HealthDesign projects, categorizing them into four topics: privacy and confidentiality, data security, decision support, and HIPAA and related legal-regulatory requirements. Discussion and resolution of these issues will be critical to successful PHR/PHA implementations in the years to come.

Fetter, M. S. (2009). Personal health records: Protecting behavioral health consumers' rights. *Issues in Mental Health Nursing, 30*(11), 720-722.

The security of electronic data worries providers, patients, and regulators. The author describes multiple efforts to protect patient privacy. Psychiatric-mental health nurses can facilitate this advance by working within practice settings and professional organizations to educate, advocate, and investigate towards this end.

Horden, A., Georgiou, A., Whetton, S., & Prgomet, M. (2011). Consumer e-health: An overview of research evidence and implications for future policy. *HIM Journal, 40*(2), 6-14.

Consumer e-health is rapidly becoming a fundamental component of healthcare. However, to date only provisional steps have been taken to increase our understanding of how consumers engage with e-health. This study, an interpretive review, assessed the evidence about consumer use of e-health and identified five categories that encompass consumer e-health: (i) peer-to-peer online support groups; (ii) self-management/self-monitoring applications; (iii) decision aids; (iv) the personal health record; and (v) Internet use. Our findings reveal that e-health offers consumers many possibilities and potential benefits, although there appears to be apprehension concerning the efficacy of some interventions and barriers relating to the trustworthiness of Internet-acquired information. It is imperative that policy initiatives address these issues to ensure that consumer e-health services can be effectively, efficiently, and safely accessed.

Kaelber, D. C., Jha, A. K., Johnston, D., Middleton, B., & Bates, D. W. (2008). A research agenda for personal health records (PHRs). *Journal of the American Medical Informatics Association*, 15(6), 729-736. doi:10.1197/jamia.M2547

Patients, policymakers, providers, payers, employers, and others have increasing interest in using personal health records (PHRs) to improve healthcare costs, quality, and efficiency. While organizations now invest millions of dollars in PHRs, the best PHR architectures, value propositions, and descriptions are not universally agreed upon. Despite widespread interest and activity, little PHR research has been done to date, and targeted research investment in PHRs appears inadequate. The authors reviewed the existing PHR specific literature (100 articles) and divided the articles into seven categories, of which four in particular--evaluation of PHR functions, adoption and attitudes of healthcare providers and patients towards PHRs, PHR related privacy and security, and PHR architecture--present important research opportunities. We also briefly discuss other research related to PHRs, PHR research funding sources, and PHR business models. We believe that additional PHR research can increase the likelihood that future PHR system deployments will beneficially impact healthcare costs, quality, and efficiency.

Li, Y. C., Lee, P. S., Jian, W. S., & Kuo, C. H. (2009). Electronic health record goes personal world-wide. *Yearbook of Medical Informatics*, 40-43.

OBJECTIVE: Increasing patient demand for convenient access to their own healthcare data has led to more personal use of the Electronic Health Record (EHR). With "consumer empowerment" being an important issue of EHR, we are seeing a more "patient-centric" approach of EHR from countries around the world. Researchers have

reported on issues in EHR sharing including concerns on privacy and security, consumer empowerment, competition among providers, and content standards. This study attempts to analyze prior research and to synthesize comprehensive, empirically-based conceptual models of EHR for personal use. METHODS: We use "B2C(2B) " to represent this new behavior of EHR sharing and exchange, with "consumer" in the center stage. RESULTS: Based on different information sharing mechanisms, we summarized the "B2C(2B) " behavior into three models, namely, the Inexpensive data media model, the Internet patient portal model and the Personal portable device model. Models each have their own strengths and weaknesses in their ways to share patient data and to address privacy and security concerns. CONCLUSION: Personal use of EHR under the B2C(2B) model does look promising based on our study. We started to observe a trend that governments around the world are embarking on related projects. With multiple stake-holders involved, we are only beginning to understand the complexity of such undertakings.

Liaw, S. T., & Hannan, T. (2011). Can we trust the PCEHR not to leak? *Medical Journal of Australia*, 195(4), 222.

This article provides a brief overview of issues related to trust and PHRs in Australia.

Lu, S. C. (2007). CCR exchange: Building a patient-driven web-based healthcare community around an emerging personal health record standard. *Studies in Health Technology and Informatics*, 127, 58-64.

This document demonstrates how we use open source software in building an Internet healthcare community around an emerging Personal Health Record standard called

Continuity of Care Record (CCR) format, and how members of the community can share healthcare information securely and efficiently while retaining total privacy.

Mytilinaiou, E., Koufi, V., Malamateniou, F., & Vassilacopoulos, G. (2010). A context-aware approach to process-based PHR system security. *Studies in Health Technology and Informatics*, 156, 201-213.

Healthcare delivery is a highly complex process involving a broad range of healthcare services, typically performed by a number of geographically distributed and organizationally disparate healthcare providers requiring increased collaboration and coordination of their activities in order to provide shared and integrated care. Under an IT-enabled, patient-centric model, health systems can integrate care delivery across the continuum of services, from prevention to follow-up, and also coordinate care across all settings. In particular, much potential can be realized if cooperation among disparate healthcare organizations is expressed in terms of cross-organizational healthcare processes, where information support is provided by means of PHR systems. This paper assumes a process-oriented PHR system and presents a security framework that addresses the authorization and access control issues arisen in these systems. The proposed framework ensures provision of tight, just-in-time permissions so that authorized users get access to specific objects according to the current context. These permissions are subject to continuous adjustments triggered by the changing context. Thus, the risk of compromising information integrity during task executions is reduced.

Pringle, S. L. (2010). Trusting PHRs. The standards that protect the security and confidentiality of PHR-stored PHI. *Journal of AHIMA*, 81(5), 40-41.

This article briefly describes existing standards around privacy and security that are related to PHRs.

Reti, S. R., Feldman, H. J., & Safran, C. (2009). Governance for personal health records. *Journal of the American Medical Informatics Association*, 16(1), 14-17.

doi:10.1197/jamia.M2854

Personal health records (PHR) are a modern health technology with the ability to engage patients more fully in their healthcare. Despite widespread interest, there has been little discussion around PHR governance at an organizational level. We develop a governance model and compare it to the practices of some of the early PHR adopters, including hospitals and ambulatory care settings, insurers and health plans, government departments, and commercial sectors. Decision-making structures varied between organizations. Business operations were present in all groups, but patients were not represented in any of the governance structures surveyed. To improve patient-centered care, policy making for PHRs needs to include patient representation at a governance level.

Ruotsalainen, P., Blobel, B., Nykanen, P., Seppala, A., & Sorvari, H. (2011). Framework model and principles for trusted information sharing in pervasive health. *Studies in Health Technology and Informatics*, 169, 497-501.

Trustfulness (i.e. health and wellness information is processed ethically, and privacy is guaranteed) is one of the cornerstones for future Personal Health Systems, ubiquitous

healthcare and pervasive health. Trust in today's healthcare is organizational, static and predefined. Pervasive health takes place in an open and untrusted information space where person's lifelong health and wellness information together with contextual data are dynamically collected and used by many stakeholders. This generates new threats that do not exist in today's eHealth systems. Our analysis shows that the way security and trust are implemented in today's healthcare cannot guarantee information autonomy and trustfulness in pervasive health. Based on a framework model of pervasive health and risks analysis of ubiquitous information space, we have formulated principles which enable trusted information sharing in pervasive health. Principles imply that the data subject should have the right to dynamically verify trust and to control the use of her health information, as well as the right to set situation based context-aware personal policies. Data collectors and processors have responsibilities including transparency of information processing, and openness of interests, policies and environmental features. Our principles create a base for successful management of privacy and information autonomy in pervasive health. They also imply that it is necessary to create new data models for personal health information and new architectures which support situation depending trust and privacy management.

Sax, U., Kohane, I., & Mandl, K. D. (2005). Wireless technology infrastructures for authentication of patients: PKI that rings. *Journal of the American Medical Informatics Association*, 12(3), 263-268. doi:10.1197/jamia.M1681

As the public interest in consumer-driven electronic health care applications rises, so do concerns about the privacy and security of these applications. Achieving a balance

between providing the necessary security while promoting user acceptance is a major obstacle in large-scale deployment of applications such as personal health records (PHRs). Robust and reliable forms of authentication are needed for PHRs, as the record will often contain sensitive and protected health information, including the patient's own annotations. Since the health care industry per se is unlikely to succeed at single-handedly developing and deploying a large scale, national authentication infrastructure, it makes sense to leverage existing hardware, software, and networks. This report proposes a new model for authentication of users to health care information applications, leveraging wireless mobile devices. Cell phones are widely distributed, have high user acceptance, and offer advanced security protocols. The authors propose harnessing this technology for the strong authentication of individuals by creating a registration authority and an authentication service, and examine the problems and promise of such a system.

Sensmeier, J. E. (2010). The journey toward a personal health record. *Nursing Management, 41*(2), 47-50. doi:10.1097/01.NUMA.0000368568.05221.5a

The purpose of this article is to define what a PHR is and describe the benefits of a PHR. It includes considerations for selection and implementation of a PHR.

Teixeira, P. A., Gordon, P., Camhi, E., & Bakken, S. (2011). HIV patients' willingness to share personal health information electronically. *Patient Education and Counseling, 84*(2), e9-12. doi:10.1016/j.pec.2010.07.013

OBJECTIVE: To assess the attitudes of persons living with HIV/AIDS (PLWH) towards having their personal health information (PHI) stored and shared electronically.

METHODS: PLWH (n = 93) in New York City completed surveys using audio computer-assisted self-interview (ACASI) that assessed willingness to share their PHI with various people and entities via a secure electronic network. The survey also included questions on satisfaction with and trust of health care providers, current health, HIV-associated stigma, and frequency of internet access. Data were analyzed with descriptive and multivariate statistical methods. RESULTS: The majority (84%) of individuals were willing to share their PHI with clinicians involved in their care. Fewer individuals (39%) were as willing to share with non-clinical staff. Willingness to share PHI was positively associated with trust and respect of clinicians. CONCLUSION: PLWH accepted clinicians' need for access to accurate information. Patients' trust in their primary care providers highlights the importance of the clinician-patient relationship which can be used to engage patients support for health information exchange initiatives. PRACTICE IMPLICATIONS: As electronic storage and sharing of PHI is increasing, clinicians and PLWH should discuss patients' attitudes towards sharing PHI electronically.

Weitzman, E. R., Kaci, L., & Mandl, K. D. (2010). Sharing medical data for health research:

The early personal health record experience. *Journal of Medical Internet Research*, 12(2), e14. doi:10.2196/jmir.1356

BACKGROUND: Engaging consumers in sharing information from personally controlled health records (PCHRs) for health research may promote goals of improving care and advancing public health consistent with the federal Health Information Technology for Economic and Clinical Health (HITECH) Act. Understanding consumer willingness to share data is critical to advancing this model. OBJECTIVE: The objective was to

characterize consumer willingness to share PCHR data for health research and the conditions and contexts bearing on willingness to share. METHODS: A mixed method approach integrating survey and narrative data was used. Survey data were collected about attitudes toward sharing PCHR information for health research from early adopters (n = 151) of a live PCHR populated with medical records and self-reported behavioral and social data. Data were analyzed using descriptive statistics and logistic regression to characterize willingness, conditions for sharing, and variations by sociodemographic factors. Narrative data were collected through semistructured focus group and one-on-one interviews with a separate sample of community members (n = 30) following exposure to PCHR demonstrations. Two independent analysts coded narrative data for major and minor themes using a shared rubric of a priori defined codes and an iterative inductive process. Findings were triangulated with survey results to identify patterns. RESULTS: Of PHCR users, 138 out of 151 (91%) were willing to share medical information for health research with 89 (59%) favoring an opt-in sharing model. Willingness to share was conditioned by anonymity, research use, engagement with a trusted intermediary, transparency around PCHR access and use, and payment. Consumer-determined restrictions on content and timing of sharing may be prerequisites to sharing. 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 (unadjusted odds ratio [OR] = 2.89, 95% confidence interval [CI] 1.10 - 7.62, P = .03). Participants over age 50 were less likely than younger participants to report

that payment would increase willingness to share (unadjusted OR = 0.94, 95% CI 0.91 - 0.96, $P < .001$). Students were more likely than nonstudents to report that payment would increase their willingness to share (unadjusted OR 9.62, 95% CI 3.44 - 26.87, $P < .001$). Experiencing a public health emergency may increase willingness to share especially among persons over 50 (unadjusted OR 1.03, 95% CI 1.01 - 1.05, $P = .02$); however, students were less likely than non-students to report this attitude (unadjusted OR 0.13, 95% CI 0.05 - 0.36, $P < .001$). 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 (unadjusted OR 0.61, 95% CI 0.38 - 0.97, $P = .04$). CONCLUSIONS: 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.

Win, K. T., Susilo, W., & Mu, Y. (2006). Personal health record systems and their security protection. *Journal of Medical Systems, 30*(4), 309-315.

The objective of this study is to analyze the security protection of personal health record systems. To achieve this we have investigated different personal health record systems, their security functions, and security issues. We have noted that current security mechanisms are not adequate and we have proposed some security mechanisms to tackle these problems.

Wright, A., & Sittig, D. F. (2007). Encryption characteristics of two USB-based personal health record devices. *Journal of the American Medical Informatics Association, 14*(4), 397-399. doi:10.1197/jamia.M2352

Personal health records (PHRs) hold great promise for empowering patients and increasing the accuracy and completeness of health information. We reviewed two small USB-based PHR devices that allow a patient to easily store and transport their personal health information. Both devices offer password protection and encryption features. Analysis of the devices shows that they store their data in a Microsoft Access database. Due to a flaw in the encryption of this database, recovering the user's password can be accomplished with minimal effort. Our analysis also showed that, rather than encrypting health information with the password chosen by the user, the devices stored the user's password as a string in the database and then encrypted that database with a common password set by the manufacturer. This is another serious vulnerability. This article describes the weaknesses we discovered, outlines three critical flaws with the security model used by the devices, and recommends four guidelines for improving the security of similar devices.

Provider Attitudes: Annotated Bibliography

Berry, J. G., Goldmann, D. A., Mandl, K. D., Putney, H., Helm, D., O'Brien, J., . . . Weinick, R. M. (2011). Health information management and perceptions of the quality of care for children with tracheotomy: A qualitative study. *BMC Health Services Research*, *11*, 117. doi:10.1186/1472-6963-11-117

BACKGROUND: Children with tracheotomy receive health care from an array of providers within various hospital and community health system sectors. Previous studies have highlighted substandard health information exchange between families and these sectors. The aim of this study was to investigate the perceptions and experiences of parents and providers with regard to health information management, care plan development and coordination for children with tracheotomy, and strategies to improve health information management for these children. METHODS: Individual and group interviews were performed with eight parents and fifteen healthcare (primary and specialty care, nursing, therapist, equipment) providers of children with tracheotomy. The primary tracheotomy-associated diagnoses for the children were neuromuscular impairment (n = 3), airway anomaly (n = 2) and chronic lung disease (n = 3). Two independent reviewers conducted deep reading and line-by-line coding of all transcribed interviews to discover themes associated with the objectives. RESULTS: Children with tracheotomy in this study had healthcare providers with poorly defined roles and responsibilities who did not actively communicate with one another. Providers were often unsure where to find documentation relating to a child's

tracheotomy equipment settings and home nursing orders, and perceived that these situations contributed to medical errors and delayed equipment needs. Parents created a home record that was shared with multiple providers to track the care that their children received but many considered this a burden better suited to providers. Providers benefited from the parent records, but questioned their accuracy regarding critical tracheotomy care plan information such as ventilator settings. Parents and providers endorsed potential improvement in this environment such as a comprehensive internet-based health record that could be shared among parents and providers, and between various clinical sites. CONCLUSIONS: Participants described disorganized tracheotomy care and health information mismanagement that could help guide future investigations into the impact of improved health information systems for children with tracheotomy. Strategies with the potential to improve tracheotomy care delivery could include defined roles and responsibilities for tracheotomy providers, and improved organization and parent support for maintenance of home-based tracheotomy records with web-based software applications, personal health record platforms and health record data authentication techniques.

Chen, Y. (2010). The role of patients in transiting personal health information: A field study. *Studies in Health Technology and Informatics*, 160(Pt 1), 3-7.

Recent consumer health informatics initiatives advocate individual access and management of personal medical records. However, little is known regarding the impact of personal access of health information on clinical practice. This paper introduces a field study investigating the usage patterns of personal health records in

medical consultations. The self-managed records provide patients with a strong sense of ownership and control over their own health information. Personal medical records have been used primarily for transiting information among different providers. This behavior changed patient-provider communication into a records sharing. Doing so effectively eliminated the potential errors in the verbal reporting process. This study indicates that patients can be effective contributors to their own health and suggest the design of health information systems to rethink the role of patients in the healthcare process and shift the responsibility of healthcare to the patients' side.

Clarke, J. L., Meiris, D. C., & Nash, D. B. (2006). Electronic personal health records come of age. *American Journal of Medical Quality*, 21(3 Suppl), 5S-15S.

doi:10.1177/1062860606287642

The authors provide background information distinguishing a PHR, from EHR, and EMR. They describe consumer and provider issues that may prevent using a PHR. The authors then go onto proposing a solution - LifeSensor, which is a Web-based PHR that is highly protected and secured via encryption, distributed data storage, authorization, and authentication. It is patient centered and patient controlled, with utility for physicians to encourage their acceptance. Only the patient has the right to grant a clinician access to his or her PHR.

Council on Clinical Information Technology. (2009). Policy Statement--Using personal health records to improve the quality of health care for children. *Pediatrics*,124(1), 403-409. doi:10.1542/peds.2009-1005

A personal health record (PHR) is a repository of information from multiple

contributors (eg, patient, family, guardians, physicians, and other health care professionals) regarding the health of an individual. 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. Pediatric health care professionals must become actively involved in developing and adopting PHRs and PHR systems. 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. Properly designed PHR systems for pediatric care can empower patients. PHRs can improve access to health information, improve coordination of preventive health and health maintenance activities, and support emergency and disaster management activities. PHRs provide support for the medical home for all children, including those with special health care needs and those in foster care. PHRs can also provide information to serve as the basis for pediatric quality improvement efforts. 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.

Council on Clinical Information Technology. (2011). Health information technology and the medical home. *Pediatrics*, 127(5), 978-982. doi:10.1542/peds.2011-0454

The American Academy of Pediatrics (AAP) supports development and universal implementation of a comprehensive electronic infrastructure to support pediatric

information functions of the medical home. These functions include (1) timely and continuous management and tracking of health data and services over a patient's lifetime for all providers, patients, families, and guardians, (2) comprehensive organization and secure transfer of health data during patient-care transitions between providers, institutions, and practices, (3) establishment and maintenance of central coordination of a patient's health information among multiple repositories (including personal health records and information exchanges), (4) translation of evidence into actionable clinical decision support, and (5) reuse of archived clinical data for continuous quality improvement. The AAP supports universal, secure, and vendor-neutral portability of health information for all patients contained within the medical home across all care settings (ambulatory practices, inpatient settings, emergency departments, pharmacies, consultants, support service providers, and therapists) for multiple purposes including direct care, personal health records, public health, and registries. The AAP also supports financial incentives that promote the development of information tools that meet the needs of pediatric workflows and that appropriately recognize the added value of medical homes to pediatric care.

Dixon, B. E., Miller, T., & Overhage, J. M. (2009). Assessing HIE stakeholder readiness for consumer access: Lessons learned from the NHIN trial implementations. *Journal of Healthcare Information Management*, 23(3), 20-25.

Personal health records (PHRs) have the potential to empower patient decision-making. Integrating PHRs into the nation's health information infrastructure via the Nationwide Health Information Network (NHIN) may accelerate their adoption and use. PHR and NHIN technical development activities are advancing, but little is known

about provider acceptance of PHR usage in this manner. Researchers conducted semi-structured interviews with organizations participating in an operational health information exchange to elicit opinions regarding such integration. The conversations identified important concerns that need to be addressed in order to achieve the vision established in the Consumer Access to Clinical Information Use Case outlined by the American Health Information Community. These challenges include provider workflow, authentication of consumer access, impact on provider-patient communication and consumer health literacy. Developers, policymakers, providers and patients should work together to confront and find solutions to these challenges to achieve the full potential of PHRs in the healthcare system.

Fricton, J. R., & Davies, D. (2008). Personal health records to improve health information exchange and patient safety. In K. Henriksen, J. B. Battles, M. A. Keyes & M. L. Grady (Eds.), *Advances in Patient Safety: New Directions and Alternative Approaches (Vol. 4: Technology and Medication Safety)*. Rockville (MD): Agency for Healthcare Research and Quality. Retrieved from http://www.ahrq.gov/downloads/pub/advances2/vol4/advances-fricton_21.pdf

The personal health record (PHR) is proposed as an innovative solution to the problems of fragmented communication and lack of interoperability among diverse electronic medical record (EMR) systems. It provides a single source (the patient's PHR) for authentication and remote access of the health information data from all EMR systems. A voluntary survey was offered to selected patients, caregivers, and health providers of the Willmar, MN, PHR project to determine if a PHR was useful to these stakeholders, and if so, what aspects of a PHR would be most helpful in caring for

patients. The survey responses revealed nearly universal interest by both patients and health providers in using the PHR regularly for accessing and exchanging health information, including medication and medical history reconciliation and patient education. The highest utilization would result from a community-based PHR implementation that was owned and controlled by the consumer and was portable among providers, plans, and employers.

Fuji, K. T., Galt, K. A., & Serocca, A. B. (2008). Personal health record use by patients as perceived by ambulatory care physicians in Nebraska and South Dakota: A cross-sectional study. *Perspectives in Health Information Management*, 5, 15.

The purpose of this cross-sectional study is to examine the awareness and engagement that ambulatory care physicians have with patients who use a personal health record (PHR). This is part of a larger study examining health information technology (HIT) and electronic health record (EHR) adoption by ambulatory care physicians in Nebraska and South Dakota. Descriptive results and inferential findings about physician awareness and engagement are presented in relationship to the physician's stage of EHR adoption, practice type and size, gender, specialty, and age. Overall, physicians' awareness of PHRs and their engagement with the technology remains low. Physicians using EHRs were more likely to be aware and engaged with PHRs than physicians who either plan to adopt EHRs or have no intention to adopt EHRs. Practice type, gender, and specialty have an association as well. The implications of the findings are discussed, and a recommendation is made that education of physicians is needed in this area as the nation progresses toward the creation of a national health information network for health information exchange.

Gaskin, G. L., Longhurst, C. A., Slayton, R., & Das, A. K. (2011). Sociotechnical challenges of developing an interoperable personal health record: Lessons learned. *Applied Clinical Informatics*, 2(4), 406-419. doi:10.4338/ACI-2011-06-RA-0035

OBJECTIVES: To analyze sociotechnical issues involved in the process of developing an interoperable commercial Personal Health Record (PHR) in a hospital setting, and to create guidelines for future PHR implementations. **METHODS:** This qualitative study utilized observational research and semi-structured interviews with 8 members of the hospital team, as gathered over a 28 week period of developing and adapting a vendor-based PHR at Lucile Packard Children's Hospital at Stanford University. A grounded theory approach was utilized to code and analyze over 100 pages of typewritten field notes and interview transcripts. This grounded analysis allowed themes to surface during the data collection process which were subsequently explored in greater detail in the observations and interviews. **RESULTS:** Four major themes emerged: (1) Multidisciplinary teamwork helped team members identify crucial features of the PHR; (2) Divergent goals for the PHR existed even within the hospital team; (3) Differing organizational conceptions of the end-user between the hospital and software company differentially shaped expectations for the final product; (4) Difficulties with coordination and accountability between the hospital and software company caused major delays and expenses and strained the relationship between hospital and software vendor. **CONCLUSIONS:** Though commercial interoperable PHRs have great potential to improve healthcare, the process of designing and developing such systems is an inherently sociotechnical process with many complex issues and barriers. This

paper offers recommendations based on the lessons learned to guide future development of such PHRs.

Grossman, J. M., Zayas-Caban, T., & Kemper, N. (2009). Information gap: Can health insurer personal health records meet patients' and physicians' needs? *Health Affairs (Project Hope)*, 28(2), 377-389. doi:10.1377/hlthaff.28.2.377

Personal health records (PHRs), centralized places for people to electronically store and organize their health information, can benefit both patients and doctors. This qualitative study of health insurers' PHRs for enrollees reveals potential benefits and challenges. Insurers' ability to put claims-based data into the PHR offers an advantage. However, consumers are concerned about sharing personal health information with insurers and about Internet security. Physicians question (1) the validity of claims data in making treatment decisions and (2) whether accessing these PHRs is worth the disruptions to their workflow. This paper offers possible solutions that may lead to more widespread adoption of insurer PHRs.

Hargreaves, J. S. (2010). Will electronic personal health records benefit providers and patients in rural America? *Telemedicine Journal and e-Health*, 16(2), 167-176.

doi:10.1089/tmj.2009.0063

PURPOSE: The objective of this study was to educate stakeholders (e.g., providers, patients, insurers, government) in the healthcare industry about electronic personal health records (PHRs) and their potential application in rural America. **METHODS:** Extensive research was performed on PHRs through standard literature search, product demonstrations, educational webinars, and fact finding via news releases.

RESULTS: Various stakeholders are eager to transform the healthcare industry into the

digital age like other industries (i.e., banking, retail). Despite low adoption of PHRs in 2008 (2.7% of U.S. adults), patients are interested in secure messaging and eVisits with their physicians, online appointment scheduling and reminders, and online access to their laboratory and radiology results. Federal agencies (e.g., Health and Human Services, Department of Defense, Veterans Affairs [VA]), popular information technology (IT) vendors (e.g., Google, Microsoft), and large insurers (e.g., Aetna) have energized the industry through pilot programs and new product announcements. 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. CONCLUSIONS: 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.

Kaelber, D. C., Jha, A. K., Johnston, D., Middleton, B., & Bates, D. W. (2008). A research agenda for personal health records (PHRs). *Journal of the American Medical Informatics Association*, 15(6), 729-736. doi:10.1197/jamia.M2547

Patients, policymakers, providers, payers, employers, and others have increasing interest in using personal health records (PHRs) to improve healthcare costs, quality, and efficiency. While organizations now invest millions of dollars in PHRs, the best PHR architectures, value propositions, and descriptions are not universally agreed upon. Despite widespread interest and activity, little PHR research has been done to

date, and targeted research investment in PHRs appears inadequate. The authors reviewed the existing PHR specific literature (100 articles) and divided the articles into seven categories, of which four in particular--evaluation of PHR functions, adoption and attitudes of healthcare providers and patients towards PHRs, PHR related privacy and security, and PHR architecture--present important research opportunities. We also briefly discuss other research related to PHRs, PHR research funding sources, and PHR business models. We believe that additional PHR research can increase the likelihood that future PHR system deployments will beneficially impact healthcare costs, quality, and efficiency.

Kim, J., & Bates, D. W. (2011). Analysis of the definition and utility of personal health records using q methodology. *Journal of Medical Internet Research*, 13(4), e105.
doi:10.2196/jmir.1781

BACKGROUND: Personal health records (PHRs) remain a relatively new technology and concept in practice even though they have been discussed in the literature for more than 50 years. There is no consensus on the definition of a PHR or PHR system even within the professional societies of health information technology. **OBJECTIVE:** Our objective was to analyze and classify the opinions of health information professionals regarding the definitions of the PHR. **METHOD:** Q methodology was used to explore the concept of the PHR. A total of 50 Q-statements were selected and rated by 45 P-samples consisting of health information professionals. We analyzed the resulting data by using Q methodology-specific software and SPSS. **RESULT:** We selected five types of health information professionals' opinions: type I, public interest centered; type II, health information standardization centered; type III, health

consumer centered; type IV, health information security centered; and type V, health consumer convenience centered. The Q-statements with the highest levels of agreement were as follows: (1) the PHR is the lifetime record of personal health information, (2) the PHR is the representation of health 2.0, and (3) security is the most important requirement of the PHR. The most disagreed-with Q-statements were (1) the PHR is a paper-based system, and (2) it is most effective to carry the PHR information in USB storage. CONCLUSION: Health information professionals agree that PHRs should be lifetime records, that they will be useful as more information is stored electronically, and that data security is paramount. To maximize the benefits of PHR, activation strategies should be developed and extended across disciplines and professionals so that patients begin to receive the benefits associate with using PHRs.

McInnes, D. K., Solomon, J. L., Bokhour, B. G., Asch, S. M., Ross, D., Nazi, K. M., & Gifford, A. L. (2011). Use of electronic personal health record systems to encourage HIV screening: an exploratory study of patient and provider perspectives. *BMC Research Notes*, 4, 295. doi:10.1186/1756-0500-4-295

ABSTRACT: BACKGROUND: When detected, HIV can be effectively treated with antiretroviral therapy. Nevertheless in the U.S. approximately 25% of those who are HIV-infected do not know it. Much remains unknown about how to increase HIV testing rates. New Internet outreach methods have the potential to increase disease awareness and screening among patients, especially as electronic personal health records (PHRs) become more widely available. In the US Department of Veterans' Affairs medical care system, 900,000 veterans have indicated an interest in receiving electronic health-related communications through the PHR. Therefore we sought to

evaluate the optimal circumstances and conditions for outreach about HIV screening. In an exploratory, qualitative research study we examined patient and provider perceptions of Internet-based outreach to increase HIV screening among veterans who use the Veterans Health Administration (VHA) health care system. FINDINGS: We conducted two rounds of focus groups with veterans and healthcare providers at VHA medical centers. The study's first phase elicited general perceptions of an electronic outreach program to increase screening for HIV, diabetes, and high cholesterol. Using phase 1 results, outreach message texts were drafted and then presented to participants in the second phase. Analysis followed modified grounded theory. 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. Patients saw little difference between messages about HIV versus about diabetes and cholesterol. Providers, however, felt patients would disapprove of HIV-related messages due to stigma. Providers expected increased workload from the electronic outreach, and thus suggested adding primary care resources and devising methods to smooth the flow of patients getting screened. When provided a choice between unsecured emails versus PHRs as the delivery mechanism for disease screening messages, both patients and providers preferred PHRs. CONCLUSIONS: 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.

Thomas, R. A., Voytilla, R., & Knutson, A. R. (2010). APhA2010 House of Delegates: Paving the way for the profession's best practices. *Journal of the American Pharmacists Association*, 50(4), 450-458. doi:10.1331/JAPhA.2010.10522

Wang, C. J., & Huang, A. T. (2012). Integrating technology into health care: What will it take? *JAMA*, 307(6), 569-570. doi:10.1001/jama.2012.102

Purpose To examine the impact of a personal health record (PHR) in patients with hypertension measured by changes in biological outcomes, patient empowerment, patient perception of quality of care, and use of medical services. **Methods** A cluster-randomized effectiveness trial with PHR and no PHR groups was conducted in two ambulatory clinics. 453 of 1686 (26.4%) patients approached were included in the analyses. A PHR tethered to the patient's electronic medical record (EMR) was the primary intervention and included security measures, patient control of access, limited transmission of EMR data, blood pressure (BP) tracking, and appointment assistance. BP was the main outcome measure. Patient empowerment was assessed using the Patient Activation Measure and Patient Empowerment Scale. Quality of care was assessed using the Clinician and Group Assessment Score (CAHPS) and the Patient Assessment of Chronic Illness Care. Frequency of use of medical services was self-reported. **Results** No impact of the PHR was observed on BP, patient activation, patient perceived quality, or medical utilization in the intention-to-treat analysis. Sub-analysis of intervention patients self-identified as active PHR users (25.7% of those with available information) showed a

5.25-point reduction in diastolic BP. Younger age, self-reported computer skills, and more positive provider communication ratings were associated with frequency of PHR use. Conclusions Few patients provided with a PHR actually used the PHR with any frequency. Thus simply providing a PHR may have limited impact on patient BP, empowerment, satisfaction with care, or use of health services without additional education or clinical intervention designed to increase PHR use.

Weitzman, E. R., Kaci, L., & Mandl, K. D. (2009). Acceptability of a personally controlled health record in a community-based setting: Implications for policy and design. *Journal of Medical Internet Research, 11*(2), e14. doi:10.2196/jmir.1187

BACKGROUND: Consumer-centered health information systems that address problems related to fragmented health records and disengaged and disempowered patients are needed, as are information systems that support public health monitoring and research. Personally controlled health records (PCHRs) represent one response to these needs. PCHRs are a special class of personal health records (PHRs) distinguished by the extent to which users control record access and contents. Recently launched PCHR platforms include Google Health, Microsoft's HealthVault, and the Dossia platform, based on Indivo. OBJECTIVE: To understand the acceptability, early impacts, policy, and design requirements of PCHRs in a community-based setting. METHODS: Observational and narrative data relating to acceptability, adoption, and use of a personally controlled health record were collected and analyzed within a formative evaluation of a PCHR demonstration. Subjects were affiliates of a managed care organization run by an urban university in the northeastern United States. Data were collected using focus groups, semi-structured individual interviews, and content

review of email communications. Subjects included: n = 20 administrators, clinicians, and institutional stakeholders who participated in pre-deployment group or individual interviews; n = 52 community members who participated in usability testing and/or pre-deployment piloting; and n = 250 subjects who participated in the full demonstration of which n = 81 initiated email communications to troubleshoot problems or provide feedback. All data were formatted as narrative text and coded thematically by two independent analysts using a shared rubric of a priori defined major codes. Sub-themes were identified by analysts using an iterative inductive process. Themes were reviewed within and across research activities (ie, focus group, usability testing, email content review) and triangulated to identify patterns. RESULTS: Low levels of familiarity with PCHRs were found as were high expectations for capabilities of nascent systems. Perceived value for PCHRs was highest around abilities to co-locate, view, update, and share health information with providers. Expectations were lowest for opportunities to participate in research. Early adopters perceived that PCHR benefits outweighed perceived risks, including those related to inadvertent or intentional information disclosure. Barriers and facilitators at institutional, interpersonal, and individual levels were identified. Endorsement of a dynamic platform model PCHR was evidenced by preferences for embedded searching, linking, and messaging capabilities in PCHRs; by high expectations for within-system tailored communications; and by expectation of linkages between self-report and clinical data. CONCLUSIONS: Low levels of awareness/preparedness and high expectations for PCHRs exist as a potentially problematic pairing. Educational and technical assistance for lay users and providers are critical to meet challenges related to: access to PCHRs,

especially among older cohorts; workflow demands and resistance to change among providers; inadequate health and technology literacy; clarification of boundaries and responsibility for ensuring accuracy and integrity of health information across distributed data systems; and understanding confidentiality and privacy risks.

Continued demonstration and evaluation of PCHRs is essential to advancing their use.

Witry, M. J., Doucette, W. R., Daly, J. M., Levy, B. T., & Chrischilles, E. A. (2010). Family physician perceptions of personal health records. *Perspectives in Health Information Management*, 7, 1d.

The purpose of this qualitative study was to examine family practice physician and staff views on the benefits of, barriers to, and use of personal health records (PHRs). Four focus groups were conducted at four family medicine practices in Iowa and included a total of 28 providers. Overall, participants seemed to view PHRs as a source of medical information for healthcare providers when the patient's medical record is not available. Providers appeared unaware of the patient-centered features available in many electronic PHRs and how such features might affect patients and their medical practice. While physicians identified numerous patient groups that could benefit from using PHRs, they also perceived several unique barriers, including the potential of PHRs to facilitate narcotic abuse, low levels of patient computer and health literacy, low levels of patient motivation, and difficulties with PHR and electronic medical record interoperability. Physicians' relatively narrow view of PHR functions and benefits and perception of barriers to using PHRs may restrict widespread support of PHR use.

Wynia, M. K., Torres, G. W., & Lemieux, J. (2011). Many physicians are willing to use patients' electronic personal health records, but doctors differ by location, gender, and practice. *Health Affairs (Project Hope)*, 30(2), 266-273. doi:10.1377/hlthaff.2010.0342

Electronic personal health records could become important tools for patients to use in managing and monitoring their health information and communicating with clinicians. 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, we found that although 64 percent have never used a patient's electronic personal health record, 42 percent 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 percent versus 46 percent). 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.

Yau, G. L., Williams, A. S., & Brown, J. B. (2011). Family physicians' perspectives on personal health records: qualitative study. *Canadian Family Physician*, 57(5), e178-84.

OBJECTIVE: To explore FPs' perspectives on the value of personal health records (PHRs) in primary care and the implementation and adoption of PHRs in Canada.

DESIGN: A qualitative design using semistructured interviews. SETTING: Southwestern Ontario. PARTICIPANTS: Ten FPs. METHODS: The 10 FPs participated in

semistructured interviews, which were audiotaped and transcribed verbatim. An iterative approach using immersion and crystallization was employed for analysis.

MAIN FINDINGS: Participants were generally positive about PHRs, and were attracted to their portability and potential to engage patients in health care. Their concerns focused on 3 main themes: data management, practice management, and the patient-physician relationship. Subthemes included security, privacy, reliability of data, workload, remuneration, physician obligations, patient misinterpretation of medical information, and electronic communication displacing face-to-face visits. Participants identified 3 key facilitators for adoption of PHR systems: integration with existing electronic health record systems, ease of use without being a burden on either time or money, and offering a demonstrated added value to family practice.

CONCLUSION: This study replicates previously published literature about FP concerns and opinions, and it further identifies remuneration as a potential barrier in Canadian fee-for-service payment models. Participants identified 3 key facilitators, which were suggested for implementation and adoption of PHRs, providing a basis for future research and development of these systems for use in Canadian family practice.

Variation by Population: Annotated Bibliography

Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbin, K. A., & Straus, S. E. (2011). Personal health records: A scoping review. *Journal of the American Medical Informatics Association, 18*(4), 515-522. doi:10.1136/amiajnl-2011-000105

Electronic personal health record systems (PHRs) support patient centered healthcare by making medical records and other relevant information accessible to patients, thus assisting patients in health self-management. We reviewed the literature on PHRs including design, functionality, implementation, applications, outcomes, and benefits. We found that, because primary care physicians play a key role in patient health, PHRs are likely to be linked to physician electronic medical record systems, so PHR adoption is dependent on growth in electronic medical record 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.

Atkinson, N. L., Massett, H. A., Mylks, C., Hanna, B., Deering, M. J., & Hesse, B. W. (2007).

User-centered research on breast cancer patient needs and preferences of an Internet-based clinical trial matching system. *Journal of Medical Internet Research, 9*(2), e13.

doi:10.2196/jmir.9.2.e13

BACKGROUND: Internet-based clinical trial matching systems have the potential to

streamline the search process for women with breast cancer seeking alternative treatments. A prototype system was developed to leverage the capabilities of a personal health record system for the purpose of identifying clinical trials. **OBJECTIVE:** This study examines how breast cancer patients perceive and interact with a preliminary version of an Internet-based clinical trial matching system, while taking into account the demands of diagnosis and treatment decision making. **METHODS:** Breast cancer patients participated in small group discussions and interacted with the prototype website in a two-phase qualitative research process. The first phase explored the experience of breast cancer patients (n = 8) with treatment decision making, initial responses to the idea of Internet-based clinical trial matching systems, and reactions to the prototype site. In the second phase, a different set of breast cancer patients (n = 7) reviewed revised website content and presentation and participated in a usability test in which they registered on the system and completed a personal health record to set up the matching process. **RESULTS:** Participants were initially skeptical of the prototype system because it emphasized registration, had a complicated registration process, and asked for complex medical information. Changing content and attending to usability guidelines improved the experience for women in the second phase of the research and enabled the identification of functionality and content issues, such as lack of clear information and directions on how to use the system. **CONCLUSIONS:** This study showed that women felt favorably about the idea of using the Internet to search for clinical trials but that such a system needed to meet their expectations for credibility and privacy and be sensitive to their situation. Developers can meet these expectations by conforming to established usability

guidelines and testing improvements with breast cancer patients. Future research is needed to verify these findings and to continue to improve systems of this nature.

Horan, T. A., Botts, N. E., & Burkhard, R. J. (2010). A multidimensional view of personal health systems for underserved populations. *Journal of Medical Internet Research*, 12(3), e32. doi:10.2196/jmir.1355

The advent of electronic personal health records (PHR) provides a major opportunity to encourage positive health management practices, such as chronic disease management. Yet, to date there has been little attention toward the use of PHRs where advanced health information services are perhaps most needed, namely, in underserved communities. Drawing upon research conducted with safety net providers and patients, the authors propose a multi-level analytical framework for guiding actions aimed at fostering PHR adoption and utilization. The authors first outline distinctive user and technical requirements that need to be considered. Next, they assess organizational requirements necessary to implement PHRs within health systems bound by limited resources. Finally, the authors analyze the overriding health care policy context that can facilitate or thwart such efforts. The conclusion notes that heightened national attention toward health information technology and reform provides a significant opportunity for initiatives whose goal is to increase widespread access to PHRs.

Kahn, J. S., Hilton, J. F., Van Nunnery, T., Leasure, S., Bryant, K. M., Hare, C. B., & Thom, D. H. (2010). Personal health records in a public hospital: experience at the HIV/AIDS clinic at San Francisco General Hospital. *Journal of the American Medical Informatics*

Association, 17(2), 224-228. doi:10.1136/jamia.2009.000315

Personal health records (PHRs) are information repositories; however, PHRs may be less available to persons in the safety net setting. We deployed a free, secure, internet-based PHR for persons receiving care at the AIDS/HIV clinic at San Francisco General Hospital. In our initial rollout, 221 persons registered for the PHR. Compared to the entire clinic, these initial users were more likely to be Caucasian, male, non-Hispanic, on antiretroviral medications, and have better control of their HIV infection. The median number of online sessions was 7 and the median session length was 4 min. Laboratory results were the most commonly accessed feature. Patients were satisfied with the PHR and more than 80% of users agreed that the PHR helped them manage their medical problems; however, some users were concerned that their health information was not accurate or secure. Patients in a safety net setting will access and use an online PHR.

Kim, E. H., & Kim, Y. (2010). Digital divide: Use of electronic personal health record by different population groups. *Conference Proceedings : ...Annual International Conference of the IEEE Engineering in Medicine and Biology Society. IEEE Engineering in Medicine and Biology Society. Conference, 2010*, 1759-1762. doi:10.1109/IEMBS.2010.5626732

Personal Health Record (PHR) has been increasingly recognized and actively promoted by the federal government, experts and industry as an important tool for improving healthcare in the U.S. However, the PHR use by patients and its utility have not been studied well. We have evaluated a web-based PHR in multiple locations covering diverse population groups. The study sites included a surgical specialty clinic, a medical specialty clinic, and a mental health clinic at the University of Washington, and

a low-income elderly housing facility near Seattle in the state of Washington. The PHR use by the low-income elderly was limited due to poor technical skills and low physical/cognitive abilities. On the other hand, the younger and affluent populations used the web-based PHR much easily and efficiently compared to the older and low-income group. They regarded managing personal health information easy while the older group struggled. As more computer literate individuals age, the next-generation elderly are certain to be more technically skilled than the current generation. Although the reduced physical/cognitive abilities due to aging would still be a challenge, more elderly people will be able to not only use a PHR system but also use it to the full extent to get the maximum benefit.

Kim, E. H., Stolyar, A., Lober, W. B., Herbaugh, A. L., Shinstrom, S. E., Zierler, B. K., . . . Kim, Y. (2007). Usage patterns of a personal health record by elderly and disabled users. *AMIA Annual Symposium Proceedings, 2007*, 409-413.

Personal Health Records (PHRs) are increasingly recognized as a strategy to improve patient-provider communication, availability of health information, and quality of care, by making the delivery of care more patient-centered. However, not much is known about the effects of self-managing personal health information (PeHI), patients' perception of PeHI and patient workflow around PeHI management. We studied PHR use in a low-income, elderly and/or disabled population for 18 months, and describe how the PHR was used through an analysis of database access server log data. Some patients may not keep their PHR up-to-date because they don't value, can't access, or don't understand certain categories of their health information. Understanding of

usage patterns can guide the development and maintenance of more usable and pragmatic PHR systems.

Kim, E. H., Stolyar, A., Lober, W. B., Herbaugh, A. L., Shinstrom, S. E., Zierler, B. K., . . . Kim, Y. (2009). Challenges to using an electronic personal health record by a low-income elderly population. *Journal of Medical Internet Research*, 11(4), e44. Retrieved from <http://www.jmir.org/2009/4/e44/>

BACKGROUND: Electronic personal health records (PHRs) are increasingly recognized and used as a tool to address various challenges stemming from the scattered and incompatible personal health information that exists in the contemporary US health care system. Although activity around PHR development and deployment has increased in recent years, little has been reported regarding the use and utility of PHRs among low-income and/or elderly populations. OBJECTIVE: The aim was to assess the use and utility of PHRs in a low-income, elderly population. METHODS: We deployed a Web-based, institution-neutral PHR system, the Personal Health Information Management System (PHIMS), in a federally funded housing facility for low-income and elderly residents. We assessed use and user satisfaction through system logs, questionnaire surveys, and user group meetings. RESULTS: Over the 33-month study period, 70 residents participated; this number was reduced to 44 by the end of the study. Although the PHIMS was available for free and personal assistance and computers with Internet connection were provided without any cost to residents, only 13% (44/330) of the eligible residents used the system, and system usage was limited. Almost one half of the users (47%, 33/70) used the PHIMS only on a single day. Use was also highly correlated with the availability of in-person assistance; 77% of user

activities occurred while the assistance was available. Residents' ability to use the PHR system was limited by poor computer and Internet skills, technophobia, low health literacy, and limited physical/cognitive abilities. Among the 44 PHIMS users, 14 (32%) responded to the questionnaire. In this selected subgroup of survey participants, the majority (82%, 9/11) used the PHIMS three times or more and reported that it improved the quality of overall health care they received. CONCLUSIONS: Our findings suggest that those who can benefit the most from a PHR system may be the least able to use it. Disparities in access to and use of computers, the Internet, and PHRs may exacerbate health care inequality in the future.

Lober, W. B., Zierler, B., Herbaugh, A., Shinstrom, S. E., Stolyar, A., Kim, E. H., & Kim, Y.

(2006). Barriers to the use of a personal health record by an elderly population. *AMIA Annual Symposium Proceedings, 2006*, 514-518.

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

Luckmann, R., & Vidal, A. (2010). Design of a handheld electronic pain, treatment and activity diary. *Journal of Biomedical Informatics, 43*(5 Suppl), S32-6.

doi:10.1016/j.jbi.2010.05.005

Effective tools for recording and analyzing data on patients' pain experience, use of pain treatments, and physical function are needed to improve communication between providers and patients with noncancer chronic pain. A handheld electronic diary (HED) that can be used throughout the day may provide more useful and accurate information about pain, treatments, and function than available paper and on-line diaries that are designed to be used once daily, weekly or less often. Based on user-specified requirements we designed and built a prototype HED with 7 modules. Diary queries are followed by multiple choice responses customized to the patients' expected responses. Usability testing confirmed user comprehension and acceptability of the queries, response sets, and interface.

McInnes, D. K., Gifford, A. L., Kazis, L. E., & Wagner, T. H. (2010). Disparities in health-related internet use by US veterans: Results from a national survey. *Informatics in Primary Care, 18*(1), 59-68.

BACKGROUND: The internet can contribute to improved access to information and services among underserved populations. Little is known about veterans' use of the internet for health, and how it is affected by socio-demographic characteristics. This knowledge gap is acute given the US Department of Veterans Affairs' (VA's) deployment of a major patient portal/personal health record system. **OBJECTIVES:** To assess the frequency and correlates of veterans' use of the internet and identify personal characteristics impeding veterans' health-related internet use. **METHODS:** Survey of 12 878 randomly selected adults from a panel of 60 000 US households. Veterans were oversampled. **RESULTS:** Of the 3408 veterans responding, 54% had used the internet and 29% had used the internet specifically for health. In multi-

variable analyses, general internet use was positively associated with younger age (OR = 0.03, CI = 0.01-0.06, oldest versus youngest group), higher income (OR = 3.12, CI = 2.10-4.63, > or = \$75 000 versus < \$25 000), more education (OR = 4.2, CI = 2.92-6.02, most versus least educated group), and better health (OR = 0.59, CI = 0.42-0.83, fair/poor versus very good/excellent). Health-related internet use was positively associated with more education (OR = 2.32, CI = 1.45-3.74, most versus least educated group), urban location (OR = 2.41, CI = 1.66-3.50), and worse health (OR = 1.85, CI = 1.16-2.95, fair/poor versus very good/excellent). CONCLUSIONS: In the first large, systematic survey of veterans' internet use we found that more education and urban location were strongly, and positively, associated with veterans' health-related internet use, even after controlling for multiple socio-demographic characteristics. Interventions may be needed for less educated and rural veterans, e.g. by providers discussing internet use with their patients, or by the VA training veterans in health-related internet use.

Ozkaynak, M., Marquard, J., Hsieh, Y., Brennan, P. F., & Zayas-Caban, T. (2007). Are lay people ready for health information exchange? *AMIA Annual Symposium Proceedings, 2007*, 1065.

The purpose of this study is to better understand lay people's readiness to participate in electronic health information exchange (HIE) by assessing their expectations and understanding towards these systems. This study continues the work of a project assessing lay people's understanding of personal health records (PHRs). Results of this exploratory work will be used to select terms to use in larger studies aimed at eliciting lay people's preferences and values related to participation in HIE.

Patel, V. N., Dhopeswarkar, R. V., Edwards, A., Barron, Y., Likourezos, A., Burd, L., . . .

Kaushal, R. (2011). Low-income, ethnically diverse consumers' perspective on health information exchange and personal health records. *Informatics for Health & Social Care*, 36(4), 233-252. doi:10.3109/17538157.2011.554930

We surveyed low-income, ethnically diverse consumers regarding their attitudes towards providers' use of electronic health information exchange (HIE) and consumer use of HIE through personal health records (PHRs). Amongst respondents (n=214), 48% had an annual household income below \$15,000 and 62% spoke a language other than English at home. A majority indicated that they supported providers' use of HIE (61%). Support for providers' use of HIE was independently associated with consumer willingness to permit health care providers other than their primary care doctor to view their electronic medical record information (odds ratio (OR)=2.92, 95% confidence interval (CI)=1.31-6.50) and beliefs that electronic health record use would improve quality of care (OR=2.70, 95% CI=1.18-6.18). Seventy-eight percent would potentially use PHRs. Potential PHR use was independently associated with Internet usage rates, (OR=4.46, 95% CI=1.77-11.22), belief that PHR use would improve their understanding of their own healthcare (OR=3.12, 95% CI=1.27-7.67) and comfort with sharing PHR data with their primary care doctor (OR=2.79, 95% CI=1.09-7.11). Low-income, ethnically diverse consumers affected by interoperable health information technology (IT) initiatives largely support using PHRs and HIE, provided these systems demonstrate benefits and address the privacy and security of their electronic health information. Although we found interest in PHRs comparable or higher than nationally representative populations, support for HIE was lower, and thus efforts will need to be

made to engage low-income and ethnically diverse consumers to participate in interoperable health IT initiatives.

Popkin, J., Kushniruk, A., Borycki, E., Guarin, D., Mozley, L., Kilarski, N., . . . Creed, W. (2009).

The eFOSTr PROJECT: Design, implementation and evaluation of a web-based Personal Health Record to support health professionals and families of children undergoing transplants. *Studies in Health Technology and Informatics*, 143, 358-363.

We describe the eFOSTr PROJECT, which has involved the design, implementation and testing of a unique Internet-based Personal Health Record (PHR) to support the families of transplant children and their healthcare providers. There are many gaps in the way that information is stored for children undergoing or about to undergo transplants. This group of children presents the most challenging exercise in information support between geographic and institutionally separated medical teams. They are, however, supported by highly motivated parents and families in life-threatening circumstances. A PHR was designed that allows for secure data entry, data storage, and easy controlled data access by the children's guardians or parents. The record includes contact and team member names, and medical data such as growth charts, immunizations, allergies, medications, lab values and scanned or digitized medical reports. Families can record the progress of their child as they would with a paper binder and customize their child's record with a photograph gallery and Internet link section for personal and general interest. Extensive computer-based testing of the PHR is complete. The system is being evaluated to determine the extent to which it meets the information needs of families and health providers in differing situations across Canada. The effectiveness of the system as a means for providing continuity of

information and education is also being assessed. To conduct these evaluations, new users are being interviewed and tracked in a qualitative longitudinal study.

Characteristics of the needs of the transplant families known to the David Foster Foundation (DFF) in Canada are described so that comparisons can be made to other patient groups who could benefit from their own adapted and specialized PHRs.

Roblin, D. W., Houston, T. K., 2nd, Allison, J. J., Joski, P. J., & Becker, E. R. (2009). Disparities in use of a personal health record in a managed care organization. *Journal of the American Medical Informatics Association*, 16(5), 683-689. doi:10.1197/jamia.M3169

OBJECTIVE: Personal health records (PHRs) can increase patient access to health care information. However, use of PHRs may be unequal by race/ethnicity. DESIGN: The authors conducted a 2-year cohort study (2005-2007) assessing differences in rates of registration with KP.org, a component of the Kaiser Permanente electronic health record (EHR). MEASUREMENTS: At baseline, 1,777 25-59 year old Kaiser Permanente Georgia enrollees, who had not registered with KP.org, responded to a mixed mode (written or Internet) survey. Baseline, EHR, and KP.org data were linked. Time to KP.org registration by race from 10/1/05 (with censoring for disenrollment from Kaiser Permanente) was adjusted for baseline education, comorbidity, patient activation, and completion of the baseline survey online vs. by paper using Cox proportional hazards. RESULTS: Of 1,777, 34.7% (616) registered with KP.org between Oct 2005 and Nov 2007. Median time to registering a KP.org account was 409 days. Among African Americans, 30.1% registered, compared with 41.7% of whites ($p < 0.01$). In the hazards model, African Americans were again less likely to register than whites (hazard ratio [HR] = 0.652, 95% CI: 0.549-0.776) despite adjustment. Those

with baseline Internet access were more likely to register (HR = 1.629, 95% CI: 1.294-2.050), and a significant educational gradient was also observed (more likely registration with higher educational levels). CONCLUSIONS: Differences in education, income, and Internet access did not account for the disparities in PHR registration by race. In the short-term, attempts to improve patient access to health care with PHRs may not ameliorate prevailing disparities between African Americans and whites.

Ross, S. E., Johnson, K. B., Siek, K. A., Gordon, J. S., Khan, D. U., & Haverhals, L. M. (2011). Two complementary personal medication management applications developed on a common platform: Case report. *Journal of Medical Internet Research*, 13(3), e45. doi:10.2196/jmir.1815

BACKGROUND: Adverse drug events are a major safety issue in ambulatory care. Improving medication self-management could reduce these adverse events. Researchers have developed medication applications for tethered personal health records (PHRs), but little has been reported about medication applications for interoperable PHRs. OBJECTIVE: Our objective was to develop two complementary personal health applications on a common PHR platform: one to assist children with complex health needs (MyMediHealth), and one to assist older adults in care transitions (Colorado Care Tablet). METHODS: The applications were developed using a user-centered design approach. The two applications shared a common PHR platform based on a service-oriented architecture. MyMediHealth employed Web and mobile phone user interfaces. Colorado Care Tablet employed a Web interface customized for a tablet PC. RESULTS: We created complementary medication management applications tailored to the needs of distinctly different user groups using

common components. Challenges were addressed in multiple areas, including how to encode medication identities, how to incorporate knowledge bases for medication images and consumer health information, how to include supplementary dosing information, how to simplify user interfaces for older adults, and how to support mobile devices for children. CONCLUSIONS: These prototypes demonstrate the utility of abstracting PHR data and services (the PHR platform) from applications that can be tailored to meet the needs of diverse patients. Based on the challenges we faced, we provide recommendations on the structure of publicly available knowledge resources and the use of mobile messaging systems for PHR applications.

Rubin, R. R., Borgman, S. K., & Sulik, B. T. (2011). Crossing the technology divide: Practical strategies for transitioning patients from multiple daily insulin injections to sensor-augmented pump therapy. *The Diabetes Educator, 37 Suppl 1*, 5S-18S.

doi:10.1177/01457217110391107

PURPOSE: To describe the benefits of continuous glucose monitoring (CGM) and continuous subcutaneous insulin infusion (CSII) systems compared with self-monitoring of blood glucose (SMBG) and multiple daily injection (MDI) therapy; to assess the benefits of sensor-augmented pump therapy (SAPT) in patients with type 1 diabetes; and to present an evidence-based practical protocol for introducing SAPT in patients with no prior pump or CGM experience. CONCLUSION: Continuous glucose monitoring and CSII have advantages over SMBG and MDI, respectively, in terms of A1C and hypoglycemia reduction. The Sensor-Augmented Pump Therapy for A1C Reduction (STAR) 3 trial demonstrated that initiating both CGM and CSII in selected adult and pediatric patients with type 1 diabetes unable to meet glycemic goals with

intensive insulin injection therapy significantly improved glucose control. In all subjects using SAPT, A1C levels fell rapidly from baseline to 3 months and remained significantly lower than among subjects in the SMBG+MDI group for 1 year. A distinguishing feature of the STAR 3 study was its stepwise protocol for systematizing education and self-management support using Web-based training modules and therapy management software. The demonstrated strengths of this education protocol recommend it as a model for implementing SAPT in the broader population of patients with type 1 diabetes who have not achieved their glycemic goals with optimized MDI therapy.

Samoocha, D., Bruinvels, D. J., Anema, J. R., Steenbeek, R., & van der Beek, A. J. (2009).

Empowerment of disability benefit claimants through an interactive website: Design of a randomized controlled trial. *BMC Medical Informatics and Decision Making*, 9, 23.

doi:10.1186/1472-6947-9-23

BACKGROUND: Individuals claiming a disability benefit after long-term sickness absence, have to undergo medical disability assessments. These assessments, often carried out by specialized physicians, can be complicated by wrong expectations or defensive attitudes of disability benefit claimants. It is hypothesized that empowerment of these claimants will enhance the physician-patient relationship by shifting claimants from a passive role to a more active and constructive role during disability assessments. Furthermore, empowerment of claimants may lead to a more realistic expectation and acceptance of the assessment outcome among claimants and may lead to a more accurate assessment by the physician. **METHODS/DESIGN:** In a two-armed randomized controlled trial (RCT), 230 claimants will be randomized to

either the intervention or control group. For the intervention group, an interactive website was designed <http://www.wiagesprek.nl> using an Intervention Mapping procedure. This website was tested during a pilot study among 51 claimants. The final version of the website consists of five interactive modules, in which claimants will be prepared and empowered step-by-step, prior to their upcoming disability assessment. Other website components are a forum, a personal health record, a personal diary, and information on disability assessment procedures, return to work, and coping with disease and work disability. Subjects from the control group will be directed to a website with commonly available information only. Approximately two weeks prior to their disability assessment, disability claimants will be recruited through the Dutch Workers Insurance Authority (UWV). Outcomes will be assessed at five occasions: directly after recruitment (baseline), prior to disability assessment, directly after disability assessment as well as 6 and 16 weeks after the assessment. The study's primary outcome is empowerment, measured with the Vrijbaan questionnaire. Secondary outcomes include claimants' satisfaction, perceived justice, coping strategy, and knowledge. A process evaluation will also be conducted. DISCUSSION: This study evaluates the effectiveness of an interactive website aimed at empowerment of disability claimants. It is hypothesized that by increasing empowerment, the physician-patient relationship may be enhanced and claimants' satisfaction and perceived justice can be improved. Results are expected in 2010. TRIAL REGISTRATION: NTR-1414.

Saranummi, N. (2009). In the Spotlight: Health Information Systems - PHR and Value Based Healthcare. *IEEE Reviews in Biomedical Engineering*, 2, 15-17.

doi:10.1109/RBME.2009.2034699

The author discusses recent progress in personal health records (PHR). The column is structured as follows: first, a look at what is driving health reform concluding with the need to make "value" the first priority. The role of citizens and patients in the value drive is then discussed. They must be empowered to act as co-producers in cooperation with healthcare professionals. Lastly, the role of the PHR and services based on the PHR will be elaborated.

Sarkar, U., Karter, A. J., Liu, J. Y., Adler, N. E., Nguyen, R., Lopez, A., & Schillinger, D. (2011).

Social disparities in internet patient portal use in diabetes: Evidence that the digital divide extends beyond access. *Journal of the American Medical Informatics Association*, 18(3), 318-321. doi:10.1136/jamia.2010.006015

The authors investigated use of the internet-based patient portal, 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, 4311 (76%) activated their accounts, and 3922 (69%), logged on to the patient portal one or more times; 2990 (53%) participants viewed laboratory results, 2132 (38%) requested medication refills, 2093 (37%) sent email messages, and 835 (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 (OR 2.6 (2.3 to 2.9); OR 2.3 (1.9 to 2.6)), as did those without an educational degree (OR compared to college graduates, 2.3 (1.9 to 2.7)). 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.

Sequist, T. D., Zaslavsky, A. M., Colditz, G. A., & Ayanian, J. Z. (2011). Electronic patient messages to promote colorectal cancer screening: A randomized controlled trial. *Archives of Internal Medicine*, 171(7), 636-641.

doi:10.1001/archinternmed.2010.467

BACKGROUND: Colorectal cancer is a leading cause of cancer mortality, yet effective screening tests are often underused. Electronic patient messages and personalized risk assessments delivered via an electronic personal health record could increase screening rates. **METHODS:** We conducted a randomized controlled trial in 14 ambulatory health centers involving 1103 patients ranging in age from 50 to 75 years with an active electronic personal health record who were overdue for colorectal cancer screening. Patients were randomly assigned to receive a single electronic message highlighting overdue screening status with a link to a Web-based tool to assess their personal risk of colorectal cancer. The outcomes included colorectal cancer screening rates at 1 and 4 months. **RESULTS:** Screening rates were higher at 1 month for patients who received electronic messages than for those who did not (8.3% vs 0.2%, $P < .001$), but this difference was no longer significant at 4 months (15.8% vs 13.1%, $P = .18$). Of 552 patients randomized to receive the intervention, 296 (54%) viewed the message, and 47 (9%) used the Web-based risk assessment tool. Among 296 intervention patients who viewed the electronic message, risk tool users were more likely than nonusers to request screening examinations (17% vs 4%, $P = .04$) and to be screened (30% vs 15%, $P = .06$). One-fifth of patients (19%) using the risk assessment tool were estimated to have an above-average risk for colorectal cancer.

CONCLUSION: Electronic messages to patients produce an initial increase in colorectal

cancer screening rates, but this effect is not sustained over time. TRIAL

REGISTRATION: clinicaltrials.gov Identifier: NCT01032746.

Tang, P. C., Ash, J. S., Bates, D. W., Overhage, J. M., & Sands, D. Z. (2006). Personal health records: Definitions, benefits, and strategies for overcoming barriers to adoption. *Journal of the American Medical Informatics Association*, 13(2), 121-126. doi:10.1197/jamia.M2025

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

Tani, S., Marukami, T., Matsuda, A., Shindo, A., Takemoto, K., & Inada, H. (2010).

Development of a health management support system for patients with diabetes mellitus at home. *Journal of Medical Systems*, 34(3), 223-228.

Recently, a patient with diabetes mellitus (DM) type 2 has been increasing in Japan. The patient should be managed not only by a specialist but also by himself focusing his attention on the improvement of his lifestyle at home. In the present study, we tried to develop a health management support system by which a diabetic patient in early stage can easily enter his daily life information, i.e. the biological information such as the data of blood sugar levels and blood pressure levels etc., the information of exercise and diet and send the information to the medical institution with a personal digital assistant (PDA). Afterwards, the patient can receive health instruction information by the physician in charge for self-care at his home with a PDA. The daily life information sent from the patient is stored in a server installed at the medical institution and analyzed. The physician can obtain the results of analysis by using a PC and send the instruction information necessary for patient management to the patient at home by using e-mail after diagnosing the patient's condition by the system. To evaluate usability of the developed patient information input system with a PDA, an experiment was conducted by corporation of 20 volunteers who were possible self management and whose age's range from 20s to 60s by questionnaire survey. As a result, almost examinees answered that lifestyle information could be easily entered by the sense like a mobile-phone and lots of positive opinions were obtained.

Teixeira, P. A., Gordon, P., Camhi, E., & Bakken, S. (2011). HIV patients' willingness to share personal health information electronically. [Willingness to share PHI was positively

associated with trust and respect of clinicians.] *Patient Education and Counseling*, 84(2), e9-12. doi:10.1016/j.pec.2010.07.013

OBJECTIVE: To assess the attitudes of persons living with HIV/AIDS (PLWH) towards having their personal health information (PHI) stored and shared electronically.

METHODS: PLWH (n = 93) in New York City completed surveys using audio computer-assisted self-interview (ACASI) that assessed willingness to share their PHI with various people and entities via a secure electronic network. The survey also included questions on satisfaction with and trust of health care providers, current health, HIV-associated stigma, and frequency of internet access. Data were analyzed with descriptive and multivariate statistical methods. **RESULTS:** The majority (84%) of individuals were willing to share their PHI with clinicians involved in their care. Fewer individuals (39%) were as willing to share with non-clinical staff. Willingness to share PHI was positively associated with trust and respect of clinicians. **CONCLUSION:** PLWH accepted clinicians' need for access to accurate information. Patients' trust in their primary care providers highlights the importance of the clinician-patient relationship which can be used to engage patients support for health information exchange initiatives. **PRACTICE IMPLICATIONS:** As electronic storage and sharing of PHI is increasing, clinicians and PLWH should discuss patients' attitudes towards sharing PHI electronically.

Tenforde, M., Nowacki, A., Jain, A., & Hickner, J. (2012). The association between personal health record use and diabetes quality measures. *Journal of General Internal Medicine*, , 424. doi:10.1007/s11606-011-1889-0

BACKGROUND: Electronic personal health records (PHRs) have the potential to

empower patients in self-management of chronic diseases, which should lead to improved outcomes. **OBJECTIVE:** To measure the association between use of an advanced electronic medical record-linked PHR and diabetes quality measures in adults with diabetes mellitus (DM). **DESIGN:** Retrospective audit of PHR use and multivariable regression analyses. **PATIENTS:** 10,746 adults 18-75-years of age with DM seen at least twice at the office of their primary care physician at the Cleveland Clinic from July 2008 through June 2009. **MAIN MEASURES:** PHR use was measured as number of use days. Diabetes quality measures were: hemoglobin A1c (HbA1c), LDL cholesterol, blood pressure, body mass index (BMI), HbA1c testing, ACEi/ARB use and/or microalbumin testing, pneumococcal vaccination, foot and dilated eye examination, and smoking status. **KEY RESULTS:** Compared to non-users, PHR users were younger, had higher incomes and educational attainment, were more likely to identify as Caucasian, and had better unadjusted and adjusted diabetes quality measure profiles. Adjusted odds ratio of HbA1c testing was 2.06 ($p < 0.01$) and most recent HbA1c was 0.29% lower ($p < 0.01$). Among PHR users, increasing number of login days was generally not associated with more favorable diabetes quality measure profiles. **CONCLUSIONS:** PHR use, but not intensity of use, was associated with improved diabetes quality measure profiles. It is likely that better diabetes profiles among PHR users is due to higher level of engagement with their health among those registered for the PHR rather than PHR use itself. PHR use was infrequent. To maximize value, next-generation PHRs must be designed to engage patients in everyday diabetes self-management.

Tuil, W. S., Verhaak, C. M., Braat, D. D., de Vries Robbe, P. F., & Kremer, J. A. (2007).

Empowering patients undergoing in vitro fertilization by providing Internet access to medical data. *Fertility and Sterility*, *88*(2), 361-368.

doi:10.1016/j.fertnstert.2006.11.197

OBJECTIVE: To study the effect of an Internet-based personal health record on the empowerment of patients undergoing IVF. DESIGN: Randomized clinical trial.

SETTING: Patients undergoing IVF and intracytoplasmic sperm injection (ICSI) in an academic research environment. PATIENT(S): We selected patients who were

undergoing an IVF or ICSI treatment, have an Internet connection, and speak fluent

Dutch. INTERVENTION(S): An Internet-based personal health record that provides patients with general and personal information concerning their given treatment and

that also provides facilities for communication with fellow patients and physicians.

MAIN OUTCOME MEASURE(S): Patient empowerment (measured as a multidimensional concept consisting of self-efficacy, actual and perceived knowledge,

and involvement in the decision process), patient satisfaction, meaning of infertility

problems, social support, anxiety, and depression. RESULT(S): A total of 91 female and 89 male participants were suitable for analysis. No significant differences were

observed in per person change in patient empowerment. We did not find any

significant differences regarding per person change in patient satisfaction, the meaning of infertility problems, social support, anxiety, and depression. CONCLUSION(S): Usage

of the personal health record did not have any effects on patient empowerment, but, at the same time, the study did not find that the personal health record had any

significant adverse effects either.

Tuil, W. S., Verhaak, C. M., De Vries Robbe, P. F., & Kremer, J. A. (2008). IVF patients show three types of online behaviour. *Human Reproduction (Oxford, England)*,23(11), 2501-2505. doi:10.1093/humrep/den275

BACKGROUND: The internet introduces new ways to deal with stress. However, it is unclear how its resources are used in everyday life. Using a web-based personal health record (PHR), we observed the patient's online behaviour and linked this to distress, theories on dealing with stress and demographics. **METHODS:** Between 2004 and 2007, all viewed web-pages were logged and categorized into 14 content types. Behavioural styles were elicited using factor analysis. These behavioural styles were subsequently correlated to data on demographics, coping mechanisms and distress from the female partner of the first 53 patient couples that used the PHR. **RESULTS:** One thousand and fifty patient couples viewed 588 887 web pages during their first treatment cycle. Factor analysis elicited three online behavioural styles explaining 66.9% of all variance in usage of the website: an 'individual information style', a 'generic information style' and a 'communication style'. The 'individual information style' correlated negatively to having paid employment (Spearman = -0.364, P = 0.007) and emotional coping mechanisms (Spearman = -0.305, P = 0.028). The 'communication style' correlated positively to having paid employment (Spearman = 0.318, P = 0.021) and anxiety (Spearman = 0.381, P = 0.005). **CONCLUSIONS:** IVF patients show three types of online behaviour. Only limited correlations exist between these styles and demographics, coping mechanisms or distress. When planning a website or portal for IVF patients, content should be adopted accordingly.

Tulu, B., & Horan, T. A. (2009). The electronic disability record: Purpose, parameters, and model use case. *Journal of the American Medical Informatics Association*, 16(1), 7-13.

doi:10.1197/jamia.M2405

The active engagement of consumers is an important factor in achieving widespread success of health information systems. The disability community represents a major segment of the healthcare arena, with more than 50 million Americans experiencing some form of disability. In keeping with the "consumer-driven" approach to e-health systems, this paper considers the distinctive aspects of electronic and personal health record use by this segment of society. Drawing upon the information shared during two national policy forums on this topic, the authors present the concept of Electronic Disability Records (EDR). The authors outline the purpose and parameters of such records, with specific attention to its ability to organize health and financial data in a manner that can be used to expedite the disability determination process. In doing so, the authors discuss its interaction with Electronic Health Records (EHR) and Personal Health Records (PHR). The authors then draw upon these general parameters to outline a model use case for disability determination and discuss related implications for disability health management. The paper further reports on the subsequent considerations of these and related deliberations by the American Health Information Community (AHIC).

Valdiserri, R. O., Nazi, K., McInnes, D. K., Ross, D., & Kinsinger, L. (2010). Need to improve routine HIV testing of U.S. Veterans in care: Results of an Internet survey. *Journal of Community Health*, 35(3), 215-219. doi:10.1007/s10900-010-9233-x

Late diagnosis of HIV infection contributes to poor medical outcomes and helps sustain

continued transmission of virus. Published evidence suggests that despite current public health recommendations, patients receiving care in the Veterans Health Administration (VHA) system are not being routinely tested for HIV infection. Using a sample of computer-literate veterans, we conducted a survey of recent testing experiences. My HealtheVet (MHV) is a secure website allowing registered Veterans to access limited personal VHA health information. Using the American Customer Satisfaction Index (ACSI) Survey, an electronic questionnaire on "health screening" was conducted in late Fall/early winter 2008-2009. A random sample (4%) of MHV users were surveyed; approximately 17% completed the survey and responses ranged from 31,237 to 33,074. Only 9% of the respondents indicated that they had been offered a test for HIV in the last 12 months compared to 83% who had been offered cholesterol screening, 65% blood sugar screening and 19% who had been offered testing for Hepatitis C virus (HCV). Of those who had been offered HIV testing, 91% indicated that they'd had the test performed. Of note, the percentage of respondents who indicated that they would "very likely" accept a test, if offered, was similar for HIV (73%), HCV (79%), cholesterol (75%), and blood sugar (75%). Although these results cannot be generalized to all Veterans in care, they suggest that routine testing for HIV has not been taking place and support recent VHA policy changes to remove barriers to HIV testing.

Wackerle, A., Blochlinger-Wegmann, B., Burkhardt, T., Krahenmann, F., Kurmanavicius, J., & Zimmermann, R. (2010). Notes on a stick: Use and acceptability of woman-held maternity notes. *European Journal of Obstetrics, Gynecology, and Reproductive Biology*, 153(2), 156-159. doi:10.1016/j.ejogrb.2010.07.019

OBJECTIVE: To provide expectant mothers with a USB stick containing their maternity notes, including ultrasound images, and to assess its use and acceptability versus conventional care with exclusively hospital-held notes. STUDY DESIGN: USB group: 200 women attending Zurich University Hospital Obstetrics Department for antenatal-to-postnatal care in 2006-2007. Controls: 200 women attending the Obstetrics Department for delivery only, after receiving conventional antenatal care elsewhere. Women were interviewed using an essentially identical postpartum questionnaire for each group, with minor wording differences. Main outcome measures: Overall satisfaction with pregnancy and delivery, feeling of safety, interest in the pregnancy, partner involvement, usefulness of USB stick in emergencies, impact on smoking behaviour, data confidentiality concerns, pregnancy and infant outcome. Stepwise multiple regression was used to identify determinants of overall impressions of pregnancy and delivery. RESULTS: Of the USB group, 98.5% wished to repeat the USB experience in a subsequent pregnancy; of the controls, 86.5% would have appreciated the experience, and 18.0% could think of situations in their pregnancy (vacation, emergencies) where the stick would have helped; 7.5% of the USB group shared their stick data with a doctor outside the Department, and 80.5% felt safer having the stick available. Along with preterm delivery and mode of delivery, the USB stick was a significant determinant of the overall positive impression of pregnancy. Primary caesarean section was (inexplicably) more frequent in the USB group. CONCLUSION: The questionnaire confirmed that issuing women with their maternity notes on a USB stick is a major advance in patient empowerment, satisfaction and safety.

Wald, J. S., Grant, R. W., Schnipper, J. L., Gandhi, T. K., Poon, E. G., Businger, A. C., . . .

Middleton, B. (2009). Survey analysis of patient experience using a practice-linked PHR for type 2 diabetes mellitus. *AMIA ...Annual Symposium Proceedings/AMIA Symposium, 2009*, 678-682.

Patient experience was assessed by survey as part of a large, randomized controlled trial of a secure, practice-linked personal health record called Patient Gateway at Partners HealthCare in Boston, MA. The subjects were patients with Type 2 diabetes who prepared for their upcoming primary care visit using a previsit electronic journal. The journal generated a diabetes care plan using patient chart information and patient responses to questions in preparation for a scheduled office visit. Review of 37 surveys revealed that a diabetes care plan took 5-9 minutes (modal) to be created by the patient and helped many patients to feel more prepared for their visit (60%) and give more accurate information to their provider (53%). Study limitations included small numbers of survey participants and a bias toward white, better educated patients with better controlled diabetes. Nevertheless, the electronic journal is a promising tool for visit preparation and process improvement.

Weinert, C., Cudney, S., & Kinion, E. (2010). Development of My Health Companion to enhance self-care management of chronic health conditions in rural dwellers. *Public Health Nursing (Boston, Mass.)*, 27(3), 263-269. doi:10.1111/j.1525-1446.2010.00852.x

Appropriate self-management support is needed to help individuals and their families meet the challenges of living with chronic health conditions. Such support is characterized by productive interactions between informed, active individuals, and

their health care providers. The purposes of this paper are to describe the challenges to achieving self-management support and a tool, My Health Companion (MHC), which was developed to meet that challenge. The MHC is a paper personal health record designed to help rural women with chronic health conditions to better manage and understand their health information. The selection of content for the MHC was based on the literature, input from health care experts, and chronically ill individuals, and its development incorporated principles of personal health record and clear communication. The MHC was anecdotally shown to be useful to rural women with chronic health conditions in preparing for and enhancing their visits with health care providers. As a source of information, the MHC had potential for: being beneficial to providers in recommending appropriate treatment; contributing to more informed health decision making by ill individuals; and serving as a vehicle for the establishment of more productive interactions that contributed to the achievement of true client-provider partnerships in health care.

Weitzman, E. R., Kaci, L., & Mandl, K. D. (2010). Sharing medical data for health research: The early personal health record experience. [From abstract for trust/security/privacy: Willingness to share was conditioned by anonymity, research use, engagement with a trusted intermediary, transparency around PCHR access and use, and payment. Consumer-determined restrictions on content and timing of sharing may be prerequisites to sharing. 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.] *Journal of Medical Internet Research*, 12(2), e14. doi:10.2196/jmir.1356

BACKGROUND: Engaging consumers in sharing information from personally controlled health records (PCHRs) for health research may promote goals of improving care and advancing public health consistent with the federal Health Information Technology for Economic and Clinical Health (HITECH) Act. Understanding consumer willingness to share data is critical to advancing this model. OBJECTIVE: The objective was to characterize consumer willingness to share PCHR data for health research and the conditions and contexts bearing on willingness to share. METHODS: A mixed method approach integrating survey and narrative data was used. Survey data were collected about attitudes toward sharing PCHR information for health research from early adopters (n = 151) of a live PCHR populated with medical records and self-reported behavioral and social data. Data were analyzed using descriptive statistics and logistic regression to characterize willingness, conditions for sharing, and variations by sociodemographic factors. Narrative data were collected through semistructured focus group and one-on-one interviews with a separate sample of community members (n = 30) following exposure to PCHR demonstrations. Two independent analysts coded narrative data for major and minor themes using a shared rubric of a priori defined codes and an iterative inductive process. Findings were triangulated with survey results to identify patterns. RESULTS: Of PHCR users, 138 out of 151 (91%) were willing to share medical information for health research with 89 (59%) favoring an opt-in sharing model. Willingness to share was conditioned by anonymity, research use, engagement with a trusted intermediary, transparency around PCHR access and use, and payment. Consumer-determined restrictions on content and timing of sharing may be prerequisites to sharing. 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 (unadjusted odds ratio [OR] = 2.89, 95% confidence interval [CI] 1.10 - 7.62, $P = .03$). Participants over age 50 were less likely than younger participants to report that payment would increase willingness to share (unadjusted OR = 0.94, 95% CI 0.91 - 0.96, $P < .001$). Students were more likely than nonstudents to report that payment would increase their willingness to share (unadjusted OR 9.62, 95% CI 3.44 - 26.87, $P < .001$). Experiencing a public health emergency may increase willingness to share especially among persons over 50 (unadjusted OR 1.03, 95% CI 1.01 - 1.05, $P = .02$); however, students were less likely than non-students to report this attitude (unadjusted OR 0.13, 95% CI 0.05 - 0.36, $P < .001$). 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 (unadjusted OR 0.61, 95% CI 0.38 - 0.97, $P = .04$). CONCLUSIONS: 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.

Weitzman, E. R., Kaci, L., Quinn, M., & Mandl, K. D. (2011). Helping high-risk youth move through high-risk periods: Personally controlled health records for improving social and health care transitions. *Journal of Diabetes Science and Technology*, 5(1), 47-54.

Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3045245/>

BACKGROUND: New patient-centered information technologies are needed to address risks associated with health care transitions for adolescents and young adults with diabetes, including systems that support individual and structural impediments to self- and clinical-care. **METHODS:** We describe the personally controlled health record (PCHR) system platform and its key structural capabilities and assess its alignment with tenets of the chronic care model (CCM) and the social-behavioral and health care ecologies within which adolescents and young adults with diabetes mature. **RESULTS:** Configured as Web-based platforms, PCHRs can support a new class of patient-facing applications that serve as monitoring and support systems for adolescents navigating complex social, developmental, and health care transitions. The approach can enable supportive interventions tailored to individual patient needs to boost adherence, self-management, and monitoring. **CONCLUSIONS:** The PCHR platform is a paradigm shift for the organization of health information systems and is consistent with the CCM and conceptualizations of patient- and family-centered care for diabetes. Advancing the approach augers well for improvement around health care transitions for youth and also requires that we address (i) structural barriers impacting diabetes care for maturing youth; (ii) challenges around health and technology literacy; (iii) privacy and confidentiality issues, including sharing of health information within family and institutional systems; and (iv) needs for evaluation around uptake, impacts, and outcomes.

Wiljer, D., Leonard, K. J., Urowitz, S., Apatu, E., Massey, C., Quartey, N. K., & Catton, P. (2010).

The anxious wait: Assessing the impact of patient accessible EHRs for breast cancer

patients. *BMC Medical Informatics and Decision Making*, 10, 46. doi:10.1186/1472-6947-10-46

BACKGROUND: Personal health records (PHRs) provide patients with access to personal health information (PHI) and targeted education. The use of PHRs has the potential to improve a wide range of outcomes, including empowering patients to be more active participants in their care. There are a number of widespread barriers to adoption, including privacy and security considerations. In addition, there are clinical concerns that patients could become anxious or distressed when accessing complex medical information. This study assesses the implementation of a PHR, and its impact on anxiety levels and perceptions of self-efficacy in a sample of breast cancer patients.

METHODS: A quasi-experimental pre-test/post-test design was used to collect data from participants to evaluate the use of the PHR. Study participants completed background and pre-assessment questionnaires and were then registered into the portal. By entering an activation key, participants were then able to review their lab results and diagnostic imaging reports. After six weeks, participants completed post-assessment questionnaires and usability heuristics. All data were collected using an online survey tool. Data were cleaned and analyzed using SAS v9.1. **RESULTS:** A total of 311 breast cancer patients completed demographic and pre-assessment questionnaires, 250 registered to use the online intervention, and 125 participants completed all required study elements. Matching the pre- and post-anxiety scores demonstrated a decrease in mean anxiety scores (-2.2, $p = 0.03$); the chemotherapy sub-group had a statistically insignificant mean increase (1.8, $p = .14$). There was no mean change in self-efficacy scores. **CONCLUSIONS:** Participants generally found the

portal easy to use; however, the perceived value of improved participation was not detected in the self-efficacy scores. Having access to personal health information did not increase anxiety levels. While these results suggest that the use of this PHR may be of benefit for informing patients, further research is required to investigate the impact on the patients experiences, their participation in their care, their relationships with the health care team, and their health outcomes.

Yamin, C. K., Emani, S., Williams, D. H., Lipsitz, S. R., Karson, A. S., Wald, J. S., & Bates, D. W.

(2011). The digital divide in adoption and use of a personal health record. *Archives of Internal Medicine*, 171(6), 568-574.

BACKGROUND: Personal health records (PHRs) offer the potential to improve the patient experience and the quality of patient care. However, the "digital divide," the population-level gap in Internet and computer access, may prevent certain groups from accessing the PHR. METHODS: We conducted a cross-sectional analysis of a PHR within a northeastern health system. We compared adopters (ie, those activating a PHR account online) with nonadopters (ie, those who see a physician offering the PHR but do not activate an account). We further categorized adopters by intensity of PHR use, measured by number of log-ins and number of messages sent to physicians' practices. RESULTS: As of September 30, 2009, among 75,056 patients, 43% had adopted the PHR since 2002. Blacks and Hispanics were less likely to adopt the PHR compared with whites (odds ratio [OR], 0.50; 95% confidence interval [CI], 0.45-0.55; and 0.64; 0.57-0.73, respectively), and those with lower annual income were less likely to adopt the PHR than were those with higher income. Compared with nonadopters, adopters were more likely to have more than 2 comorbidities (OR, 1.27; 95% CI, 1.17-

1.30). Use of an aggressive marketing strategy for PHR enrollment increased adoption nearly 3-fold (OR, 2.92; 95% CI, 1.58-5.40). Intensity of use was best predicted by increasing number of comorbidities, followed by race/ethnicity (whites more than blacks and Hispanics) and insurance status. We found no association between income and log-in frequency or secure messages sent. CONCLUSIONS: 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.