

APPENDIX A

Table 1: Review of Literature Summary on Consumer Perspectives of Personal Health Records

Author, Year	Design	Research Question(s)	Sample & Setting	Measures/ Variables	Findings
Abramson, Patel, Edwards, & Kaushal (2014)	Cross-sectional survey	To characterize consumer attitudes toward PHRs in 4 diverse communities across New York State	Survey from 701 consumers in four diverse communities across New York state.	Functionality	Results indicated 74% of respondents expressed interest in using a PHR, viewing medical records (67%) and the ability to have access to family member's medical record (61%). The majority (66%) indicated PHR usage would improve understanding of their health, provide a sense of control (65%) and increase satisfaction (58%), safety (59%) and quality (63%) with health care (58%).
Emani et al. (2012)	Survey	To conduct an exploratory empirical study on the applicability of the model to the study of perceptions of PHRs.	760 surveys from PHR users of ambulatory care practices of two academic medical centers at Partners Health Care in Eastern Massachusetts.	Functionality	The ease of use and relative advantage of the PHR were the most important domains among perceptions of PHR use. Four factors identified by the model were ease of use, relative advantage, observability and trial ability (or the extent to which the innovation can be subject to experimentation).
Fricton and Davies (2008)	Mailed voluntary survey	Evaluation of PHR features for increased utilization and improve healthcare safety and quality.	182 Congestive Heart Failure patients involved in a collaborative rehabilitation initiative in Willmar, MN.	Usefulness accessibility education.	Recommended features included: Organizing health records (91%), availability of online calendars' and reminders (74%), personalized health education (71%), access to community services (69%), online health communication with providers and health plans (60%) and health care cost

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					management (57%)
Kerns et al. (2013)	Focus groups	Identification of necessary elements for patient engagement in advanced interactive PHRs.	Three focus groups involving a total of 14 PHR users and two groups of non-users totaling 14 participants from eight practices of Virginia Ambulatory Care Outcomes Research Network.	Security ,privacy , accessibility and functionality.	Nearly all participants discussed three components of trust: security, privacy and accuracy. Most participants strongly opposed to PHRs developed by commercial entities and sharing of health information with insurance company. Many participants mentioned that the critically important feature of PHR was the accessibility for patients.
Keselman et al. (2007)	Online survey	Survey of patients' experience with reviewing their health records, in order to identify barriers to optimal record use.	104 unpaid volunteers completed the survey between Dec 19, 2006, and Feb 1, 2007.	Ease of use, usefulness.	Responses to the survey indicated that patients wanted to view: • Laboratory results (85%); • Radiology results (63%) • Physician's notes (58%) • Diagnostic images (52%) Nearly half (48%) felt the navigation was easy and 76% reported that viewing PHR helped them in health decisions.
Lam, Lin, Senelick, Tran, Moore & Koretz (2013)	Cross Sectional	Evaluation of attitudes and preferences of adults related to health information exchange with providers.	324 adults using an Internet-based secure messaging system with providers.	Attitudes, satisfaction and preferences.	Favored provider communication via email, verified systems was easy to use.
Liu and Hayes (2010)	Semi structured interviews	Evaluation of three PHR systems for usability.	18 patients from three clinics (18 to 55 years old) with a range of technical and medical experience and no previous PHR experience.	Functionality navigation privacy & security.	Themes identified from responses: • Use of "medical jargon" was difficult to understand. • Keep language as simple as possible. • Difficulty in keeping track of the system with updates, record status, interfaces.

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					Privacy, security and trust issues. There was a potential for patient created mistakes from the power and complexity of the system. Accuracy of the data is fundamental in adhering to recommendations and interventions.
Lober et. al. (2006)	Descriptive study	Evaluate the barriers faced by a low income, elderly population in creating and using a personal health record.	38 residents of a publicly subsidized housing project.	Usability - access - usage - computer literacy - computer anxiety	Participants had a mean age of 69 with 82% being female and many chronic diseases. Computer literacy (63%) and computer anxiety (58%) were the top barriers identified. The majority (82%) printed copies of their PHR for their provider visit.
Maloney & Wright (2010)	Descriptive	Compare commercial Personal Health Record (PHR) devices.	13 U.S.-based commercial PHRs.	Clinical elements	Commercial based PHR's contain many deficiencies and lack teaching resources, emergency entry, summaries and the ability to import/export data. Recommended tethered PHRs as a better option.
Markle Foundation (2008)	Public Opinion Survey	Explore consumer perceptions about PHRs.	1,580 adults (18+) nationwide, from May 13-22, 2008.	Perceptions, privacy practices, adoption and utilization.	Majority of respondents (79%) believed using an online PHR would provide major benefits to individuals in managing their health and health care services. Nearly half (46.5 %) indicated they would be interested in using an online PHR service whereas 56.8 % cited worries about privacy and confidentiality as a reason for their reluctance
Nazi (2009)	American Customer Satisfaction Index	Measure satisfaction and elicit information about characteristics and preferences of My	100,617 random sample of site visitors who navigated at least four pages on	Usability - navigation - satisfaction Privacy and	Satisfaction scores were high (8.3/10) and site was recommended to other veterans (9.1/10). The majority (75%) requested online VA prescription refills

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	survey	HealtheVet PHR adopters.	the site from October 2007 to October 2008.	security.	as the most important feature and 87% desired to view upcoming appointments. 64% like online secure communication with provider. More than half (56%) agreed that using MyHealtheVet has improved their ability to manage their health.
Ngyugen (2011)	Focus groups	Views and issues influencing adoption of online personal health records.	29 young healthy adults (18-34) living in Montreal, Canada.	Functionality, adoption, security and privacy.	Half (51.7%) of respondents thought it would be “very useful” or “extremely useful” in helping manage health issues. Privacy related to the internet was a concern (31%). Respondents emphasized <i>accessibility</i> of health information important.
Ozok, Wu, Garrido, Pronovost, & Gurses (2014)	Multi method approach – observation interviews, survey and focus groups	Usability and perceived usefulness of PHRs for preventive healthcare : patient’s perspectives.	Focus groups in a suburban primary care clinic. N=29.	Functionality, use, ease of use, navigation.	Responses were positive regarding the usefulness of the survey (on a Likert scale 4.9/7). Indicated that PHR helped in better understanding of the consequences of unhealthy life style. Themes from qualitative analysis were individualized information, continuity of care, patient activation and improved communication with providers, Negative perceptions included: unable to understand medical terminology, difficulty in remembering medical histories and inaccurate information.
Patel et al. (2011)	Telephone survey	Consumers' attitudes about PHRs, electronic tools that enable consumers to securely access, manage, and	200 adult residents of New York state’s greater Buffalo region.	Functionality, adoption and navigation.	Majority of respondents (70%) indicated they would use PHRs. Consumers wanted PHRs to incorporate an array of information, including immunization records (89%) and providers visited

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		share their health information.			(88%). They expressed interest in several online activities, including accessing their family members' healthcare information (71%).
Roblin et al. (2009)	Online and written survey	Disparities in Use of a Personal Health Record in a Managed Care Organization.	Cohort sample of 25-59 year old Kaiser Permanente Georgia enrollees, who had registered with KP.org, between Oct 2005- Nov 2007survey. N=1777.	Self-reported race/ethnicity and education.	Whites (41.7%) were the majority who registered to use PHR, while blacks accounted for 30.1% and others included 27.1%. Age range with the most registration was 55-59 (38%) while in education post graduates had the majority percentage (44.4%).
Segall et al. (2011)	Surveys and interviews	Evaluate the usability and functionality of HealthView PHR.	20 volunteer participants from Duke University Health System, age from 27 to 84 (average, 53).	Usability Functionality	Commonly accessed information included medications (81%) and general health (86%) content, as well as information about their own medical conditions (86%). The majority (86%) were interested in managing more aspects of their health online, including reviewing their allergies and immunizations, emailing their physicians, accessing medical reports, reading about medications and general and patient-specific health issues, and tracking their health conditions.
Silvestre, Sue, & Allen (2009)	Online email survey	Consumers' acceptance of online health services.	1,702 registered members of Kaiser Permanente's online member registration database from 2004 – 2008.	Web activity, ease of use, usefulness and quality.	Inclusion of online test results and e-mailing doctor's office in PHR functionality increased the web site registration from 9% in 2005 to 27% in 2008. Six most visited features of PHR frequently visited were prescription

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					refills, online appointment transactions, facility directory and health encyclopedia visits. Over half of the participants (57%) indicated the PHR was useful and a quality application.
Spil and Klein, (2014)	Interview	Explanations why Google Health failed and predictions relative to Microsoft's ability to reach a tipping point with respect to produce/service viability.	51 Users of Google Health (27) and Microsoft Health Vault (24).	Usability - perceived usefulness - user friendly - access - timeliness Quality	Participants viewed both systems quality and service quality positively while the perceived usefulness had a negative effect. Participants did mention the system was user friendly and provided easy accessibility, quality of data and timeliness of system responses.
Somner, Sii, Bourne, Cross, 7 Shah (2013)	Focus group & interviews	What patients with glaucoma think about PHRs and what type of information a glaucoma PHR should contain.	71 Glaucoma patients	Usefulness and functionality.	Participants suggested that PHR facilitate communication and coordination of care. Some participants (36%) wanted to look at more information on medication. The group discussion indicated that PHR can help as an educational tool, engage patients in their care, provide information about their care and promote interaction with the healthcare team.
Stoylar (2011)	Interviews	Knowledge about PHRs and PHR adoption from the health care consumer perspective.	32 subjects from the University of Washington Human Subject Division on September 21, 2007.	Usefulness, interest level, adoption, privacy and security.	The majority of participants (60%) had used PHR at least once but 40% had never used a PHR. Many (34%) indicated that they were mostly interested in managing their health information via PHR.
Viand (2014)	Paper-based	To evaluate the perceived usefulness and perceived ease of	Convenience sampling of 30	Usability and functionality.	Participants provided feedback about module design, content and functionalities. Of the study users 60%

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	surveys	use of the PHR and its effect on user intention to use.	pregnant women.		perceived the PHR useful and easy to use.
Wagner, et al. (2014)	Survey with Adult Literacy in Medicine test (REALM)	To examine the impact of PHR in patients with HTN.	PHR and no PHR groups were from two ambulatory clinics. N= 443.	Security measures, patient control of access, limited transmission of EMR data, blood pressure (BP) tracking, and appointment assistance.	As age increased by 4 years, PHR use decreased by 4%. Greater PHR use was associated with self rated computer skills, self reported internet use items, higher average Diastolic Blood Pressure and higher provider communication scores. Utilization was only 26%. Users of PHR had a reduction of 5.25 points in diastolic blood pressure and 3.97 points in systolic blood pressure.
Wagner, et al. (2010)	Interviews	Examine patient perspectives on ePHR use and functionality as part of the development process of an existing ePHR, to assess whether or not these ideas are technologically feasible	Convenience sample of 31 ambulatory patients with hypertension attending a family medicine clinic N=31	Usability, functionality, expectations	The majority of suggestions (76%) regarding specific utilities and functionality were regarded as relevant by the collaborative team and 50 % of the suggestions in the Technology Theme were viewed as technologically feasible and subsequently implemented into the ePHR.
Wen, Kreps, Zhu, & Miller (2010)	Probability survey	To examine consumer attitudes toward PHRs and their healthcare providers' use of HIEs, as well as to evaluate consumer use of the Internet for tracking PHRs.	Publicly accessible 2007 HINTS developed by the National Cancer Institute, a biennial national probability survey of US civilian non institutionalized adults N=7674	Accessibility, usability	The majority of participants (86%) rated electronic access to PHRs as important. The Hispanic population more highly valued the concept of ePHR than white respondents. Consumers perceived PHRs as a compensating tool for gathering their personal health information.

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Yamin et al. (2011)	Cross-sectional study	Identification of digital divide and the adoption of PHR	Patients who received care from PHR-enabled Partners HealthCare primary care practices between January 1, 2007, and September 30, 2009 N= 75,056	Adoption, frequency of use	The white population (84%) were the highest adopters, while 9% of racial minorities (Black, Asian and Hispanic) used the PHR. Patients from 51 to 65 years of age composed the majority of the high user group at 41%.