Evidence Base for Personal Health Record Usability[1]
Final Report to the National Cancer Institute

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Executive Summary

Three factors are converging to motivate a more consumer-centered approach to health information. Near universal penetration of information technology in homes and work places, strong demands by some patients to have access to their own health information to participate with health care professionals in health care decision making and management, a trend toward an even larger group of consumers and patients to be active participants in decisions about their health and health care and spiraling health care costs are driving development of Personal Health Record (PHR) systems. PHRs generally include information and communication resources specific to an individual's health and health care. PHRs are gaining widespread attention as they take electronic form and potentially link to medical health records. The complexity of health concepts and terminology and the large number and variety of health conditions makes using PHRs challenging for consumers and, especially so, for those with little computer skill and who have health conditions that limit electronic interactions. As PHRs are disseminated more widely, characteristics of the PHRs themselves may propel consumers and patients toward those that are more user-oriented. The adoption and effectiveness of PHRs will depend as much on systems and user interfaces as on the data in the records.

Usability is crucial to adoption and effective use of all types of information technology innovations, especially in Internet-based applications where help is not available and where many alternatives are a click away. This project aimed to develop an evidence-based framework for usability guidelines. The focus was on grounding the guideline framework in consumer needs assessments and in adding to the usability evidence for the important function of viewing and understanding information displayed in a PHR. A literature review, survey of existing PHR system features, design mockup, and four focused usability studies were completed and synthesized to yield a framework for usability guidelines.

A review of the literature on PHR usability yielded a small set of empirical studies. Of the retrieved articles, only eight focused on patients as users; 44 focused on health care professionals as users, and the remainder focused on specific technical innovations, design related methods, or PHR/EMRs in general. In 2006, the Markle Foundation identified more than 167 different PHR products. Examination of those that are publicly accessible led us to conclude that using a PHR requires three substantial kinds of experience: computer experience (to understand basic interaction mechanisms, such as using menus and

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[1] This report and other papers and materials are available at http://ils.unc.edu/phr

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tabs, entering data in forms, importing external files, and opening, saving, and backing up the application and data), health information experience with medical health concepts and terminology; and personal record keeping experience to recall or find the information needed to create the PHR records and to update the systems so the data are useful and personally relevant.

Interviews with 43 people identified a number of features that should be included in PHRs to ensure acceptance by a broad range of potential users. While there is good consensus about the content of PHRs and the ways in which they might be used, there was little agreement about who should hold and maintain an individual's records. In addition to the range of uses and types of information, usable PHR systems must also support secure and persistent access over time.

Two experiments involving 106 participants focused on presentation format (tables, bar charts) for laboratory test result conditions (number of values, range and normality of values). These studies demonstrate that display presentation has strong effects on how people read and understand test results. Risk perceptions, an important factor in health behavior, are influenced by well-specified communication of test results. These conclusions are consistent with reviews conducted about risk perceptions and the communication of risk.

A qualitative study with 30 participants over age of 55 focused on medication management factors (drug name, dosage, frequency) and visualization techniques (list, bar chart, calendar). Visualization preferences were found to depend on task. The preferred visualization techniques were superior to human memory for recalling medication information details, both in accuracy and in speed. Medication information should be online so that it can be updated from pharmacies and health institutions, and available and shareable at multiple locations, including with different kinds of devices.

A laboratory study was conducted with 192 participants (half young adults, half older adults) to determine the effects of level of interactivity and screen complexity. Increased levels of interactivity and information complexity showed effects on both cognitive and affective measures, with stronger effects in older adults. Older adults tended to spend significantly more time going through the stimulus PHR website than did younger adults. In general, the benefits of providing interactive information (especially with increasing levels of information complexity) were more palpable among younger adults than with older participants, who expressed greater frustration and concern while navigating the interface.

User studies and surveys of the literature and existing PHR systems demonstrate several general conclusions that will influence usability. First, PHR systems are inherently complex because people's states of health and their illnesses are deeply complex, and because health care involves many people (e.g., various clinicians and health care providers, family) and organizations (e.g., health insurance companies, hospitals, clinics). Health information is personal, and the physical and mental implications of health conditions strongly influence perceptions and behaviors. Thus, not only are there a large variety of possible information types and actors, but much of this information must be held in confidence, thereby requiring additional considerations for usage. This overall complexity of health information is far beyond the kinds of records (e.g., financial, social) that people typically manage in their lives. This complexity suggests a divide-and-conquer, layered strategy for usability.

Second, personal health information is relevant to all people, regardless of their experiences with human health or technology, socioeconomic status, age, and physical and mental conditions. Designing usable systems for everyone often leads to lowest common denominator solutions and eventually to strong standards for basic functionality. In the early stages of PHR development, the usability solution for the complexity and universality posed by PHR systems suggests customization paths for users. This is especially important with older users and people with specific chronic health conditions. It is likely that people will bring very different needs, experiences, demands and expectations to their encounters with PHRs.

Third, using personal health information is a life-long endeavor. The health record extends over many years and likely becomes even more important later in life when parents, spouses, and clinicians may not be available to inform decisions that benefit from past health history and when there are likely to be more health issues. The need for persistent records over time raises usability issues related to digital preservation and maintenance of effective archives.

With these constraints in mind, a three-dimensional usability guideline matrix is proposed that crosses PHR functionality, data types, and specific usability issues. Functionality classes include: enter data (direct or download), find data, exchange data (send and receive, including local devices), view data, analyze and make sense of data, make decisions (information, tools), communicate (appointments, referrals, email/social networks), alerts and reminders, manage financial information, and manage the PHR as a system (e.g., security, preferences). Data types include: personal information (individual, family, health care providers and contact information, insurers, history, pets), complaints (problem list), clinical encounters, diagnoses, procedures (surgeries, treatments), lab results, immunizations, allergies, medications, advance directives, nutrition and diet, exercise, personal commentaries, information resources (literature, glossaries, encyclopedias, webpages, listservs), and financial data. PHR-specific usability issues include: complexity (layout, vocabulary, number and nature of action options); interaction and control (data input, data output, system management, data management, help); and user characteristics (accessibility, compatibility and flexibility).

This framework can be used to construct a set of usability guidelines that will be highly sparse with respect to evidence in the beginning. As PHRs are developed and used, it may be possible to prioritize the specific cells of the matrix in order of importance and to add strength of evidence ratings from the literature.

Personal Health Information Context

Information technology is strongly affecting how people access and manage health information. A Pew Internet and American Life survey in December 2005 found that one fifth of Americans who access the Internet reported that the Internet has “greatly improved the way that they get information about health care.” An earlier survey (March 2005) reported that 17 million Americans found that the Internet “played a crucial or important role as they helped another person cope with a major illness.” (Madden & Fox, 2006). The Health Information National Trends Survey (HINTS, 2003) found that almost half of all Americans have sought cancer information at some time. There were substantial differences between where people prefer to obtain cancer-related information (half preferred to go to health care professionals) and where they actually get this information (almost half used the Internet while only 11% used health care professionals).

Concomitant with access to Internet-based information resources is the growing attention to medical health records (MHRs) that allow health care professionals to manage and exchange patient information (National Committee on Vital and Health Statistics, 1998, 2001, 2006; Lohr, 2005). The vast potential market, among both consumers and providers, and the importance of health information, insures that such integrated tools will become more common in the years ahead as consumers, advocates, various organizations, policy makers and political leaders influence the health care industry to cooperate toward these ends. It is this cooperation requirement that most constrains MHR adoption. Thus progress is slow in spite of powerful political and economic advocacy.

Three factors are converging to motivate a more consumer-centered approach to health information. Near universal penetration of information technology in homes and work places, strong demands by some patients to have access to their own health information to participate with health care professionals in health care decision making and management, and spiraling health care costs are driving development of Personal Health Record (PHR) systems. A recent survey conducted for the Markle Foundation (Markle, 2006a) reported that two-thirds of Americans across the socio-economic spectrum are interested in accessing some aspect of their own health information electronically. PHRs allow people to manage their own health information, sometimes in conjunction with their health care providers or health care payers’ MHR systems (Hearings, 2005; Cognetti & Cecere, 2003; Ueckert et al., 2003; Wald et al., 2004; Markle Foundation, 2006a; Tang et al., 2005; Burrington-Brown et al., 2005).

PHRs, that generally include information and communication resources specific to an individual’s health, are gaining widespread interest as they take electronic form and potentially link to medical health records (MHRs). One explanation of the PHR is: “an electronic, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR does not replace the legal record of any provider” (Burrington-Brown et al., 2005)**.** The Markle Foundation (2006b) provides an extensive definition of PHRs (p 28-33) that distinguishes them from Electronic Health Records (MHRs), includes a variety of stakeholders, and stresses that they are actively used rather than simply repositories for information. In the literature, the integration of personal health information and the systems to manage and access this information are often referred to as PHRs. Thus, although personal health information may take the form of paper, the general assumption is that PHRs are primarily electronic systems that contain the information.

While ‘PHR’ is used to characterize the overall category, it is clear that PHRs include different classes of information and tasks that users can access and perform. Keeping in mind that most of the literature is generated by health care professionals, the most widely described potential uses for PHRs are:

review/update medical records; make/change appointments; request referrals and prescriptions/refills; review laboratory results; email physicians and other health professionals; solicit and obtain generic and/or personalized health advice, participate in chats, online discussion and support groups and receive decision support for medical choices (Cimino, Patel, & Kushniruk, 2002; Endsley et al., 2006; Wald et al., 2004).

Baur noted in the National Health Information Infrastructure (NHII) hearings, "Personal health records are a unique mechanism to engage individuals at different life stages, in their own health, and [they are also] a novel platform for prevention activities that could include information, recommendations and attitudinal and behavioral messages" (Hearings, 2005). PHRs have the potential not only to provide information to patients but also to empower them for self-management functions needed to manage acute and chronic illnesses and to facilitate improved communication between physicians and patients (Cognetti & Cecere, 2003; Ueckert, et al., 2003; Wald et al., 2004). Information in electronic form depends on technology for access, display, and transmission. Thus, the term 'PHR' typically includes the electronic system that enables use as well as data in the record. **The adoption and effectiveness of PHRs will therefore depend as much on systems and user interfaces as on data in records.** Consumers of health information may expect tools, like *Quicken* (http://quicken.intuit.com/), that integrate different kinds of information relatively seamlessly. In the case of financial data, this includes home-generated, bank-generated, and government-generated data through largely invisible-to-the-user standard formats and exchange protocols. Although PHRs now may be accessible only to affluent and middle class populations, this is likely to change. A recent study by Ross and colleagues (2005) found that patients in community health centers were as likely as those in academic medical centers to endorse shared medical records and Internet-accessible records for patients. A recent AARP Public Policy Institute report reviewed 24 PHRs and found that although adoption is currently low, there is considerable interest on the part of patients as well as providers (Cronin, 2006).

PHR Usability

There is considerable advocacy for Personal Health Records (Burrington-Brown et al., 2005; Hearings, 2005; Cognetti & Cecere, 2003; Ueckert et al., 2003; Wald et al., 2004), and some evidence for their adoption or effectiveness (Cimino et al., 2000; Garrido et al., 2005; Hassol et al., 2004; Pyper at al., 2004; Tobacman & Nolan, 1996). At this early stage in the development of PHRs, adoption and use can be strongly influenced by evidence-based guidelines that reduce the complexity of the possible design space, thus saving development costs and conserving opportunity costs for early adopters. One factor that will influence their adoption and use is their *usability* by diverse groups of people with varying levels of health knowledge and technological experience. The many dimensions of usability [learnability, efficiency, memorability, errors, and satisfaction] (Nielsen, 1993) play an important role in technology adoption and use (Mackie & Wylie, 1988; Venkatesh et al., 2003; Landauer, 1995; Norman, 1998). This role is demonstrated by the information technology industry's increasing investments in usability engineering and testing (e.g., Karat et al., 2004).

Usability is crucial to adoption and effective use of all types of information technology innovations (Nielsen, 1993; Mayhew, 1999;) especially in Internet-based applications where help is not available and where many alternatives are a click away (Bias & Mayhew, 2005; Shneiderman & Plaisant, 2005). For software, usability is determined by the human-computer interface and there is growing attention to usability testing as part of return on investment decisions (e.g., Karat et al., 2004; Marcus, 2005). In the health area, usability issues have been stimulated by the Institute of Medicine's report of 2000 that medical errors are a major cause of death (Kohn, Corrigan, & Donaldson, 2000), which startled the nation, and by demographic trends of aging baby boomers with IT experience (Marcus, 2006). Although medical errors are due to a variety of factors (Gawron et al., 2006, organize these factors into legal-regulatory-cultural; organization; social, physical, ambient, provider, patient, and device categories), there are numerous examples of how poorly designed user interfaces in health care environments have led to tragic outcomes, even when health care professionals use these interfaces regularly (e.g., Nielsen, 2005). The Therac-25 radiation burns due to poor hardware-software user interface design is classically discussed in human factors literature and courses (Leveson & Turner, 1993), but the impact of poor displays and data entry interfaces have much broader implications for applications such as medication ordering (e.g., Koppel et al., 2005). Horsky et al. (2005) argued for increased adoption of cognitive science-based usability engineering and testing to reduce medical errors by health care professionals.

The possibilities for errors are much more problematic for consumers who may not regularly use PHR interfaces, may not understand medical or technical terminology, and who enter their own data (e.g., Kim & Johnson, 2004). Thus, PHR usability is an acute issue. Although there are studies on the usability of MHRs by health care professionals (e.g., Hanzlicek, et al., 2005; Pizziferri et al., 2005; Rodríguez, et al., 2002; Rose et al., 2005) and a few that report how patients interact with MHRs (e.g., Binsted et al., 1995 studied how patients learned about diabetes with a system linked to their medical records and Cawsey et al., 2000 extended this model to cancer patients), there are few studies that consider how patients use emerging PHR systems. This is an important concern with PHRs as Tang et al. (2006) note: “Consumer-related interface, technology, and access issues specific to PHRs are not yet well-understood.” At this early stage in the development of PHR systems, evidence for basic usability will strongly influence adoption of PHRs.

PHR usability is especially challenging because older people could be some of the most active users. This will become increasingly important as people over the age of 65 are expected to make up one fifth of the US population by 2030 (Federal Interagency Forum on Aging Related Statistics, 2006). Newell et al. (2006) provide a case study of an information portal for older users and identified key usage problems older people exhibit, including: difficulty making sense of content, unfamiliarity with user interface conventions (e.g., menu use, scrolling, clicking sequences), difficulty using a mouse (e.g., moving, clicking, double clicking, dragging, tracking hand and pointer), difficulty with jargon (e.g., properties, contacts), and difficulty remembering fine grained details about usage. Clearly, PHR designs must also pay careful attention to age-related abilities and preferences.

The confluence of health care advances, longer life spans, rising health care costs, and information technology penetration into the mainstream work habits of first-world citizens has stimulated enormous interest and investments in electronic systems to improve health care professionals’ productivity and enable consumers to become more actively involved in health management. EMRs and PHRs are logical products of this confluence. EMRs are the health care system’s response to this confluence, and PHRs are the end user and consumer advocacy response. This report summarizes a project devoted to investigating the state of PHR usability with an eye toward a framework for usability guidelines.

The Personal Health Record Usability Project

The National Cancer Institute has a long-term commitment to user-centered information research (UCIR) and has been a leader in developing communication campaigns to improve healthy behavior. As more health information becomes available in electronic forms and as more people seek and use health information online, the usability of the electronic systems becomes more crucial. NCI has been a leader in usability, as evidenced by its development of the *Research-based Web Design & Usability Guidelines* available at usability.gov (Koyani et al., 2003). NCI plans to build upon this success by integrating consumer health informatics with its advanced bioinformatics functions. NCI aims to develop a UCIR emphasis that includes components for bioinformatics, medical informatics, and consumer health informatics (Hesse, in press). Consumer health informatics is perhaps the least developed of these components but has the largest potential to affect the public’s health care decisions because it directly addresses the entire population rather than only health care professionals. One aspect of this effort is to define a consumer health informatics UCIR emphasis. To this end, the Health Communications and Informatics Research Branch funded a research project to develop a procedure for creating a set of usability guidelines for electronic personal health record (PHR) development, maintenance, use and sharing. Because the electronic PHR requires a technical platform for use, the term PHR used in this report refers to the physical (input/output devices) and conceptual interface (information organization and interaction patterns) aspects of these platforms. The project was conducted as an interdisciplinary effort, involving faculty from the University of North Carolina at Chapel Hill's Schools of Public Health (SPH), Information and Library Science (SILS), Medicine (SoM), and Journalism and Mass Communication (SJMC). This report summarizes the findings and makes recommendations for PHR usability research and development.

Aims and Activities

Two primary aims motivated the project:

- Define a procedure for developing a set of usability guidelines for PHR development, use, and sharing; and
- Relate this work to the Health Maintenance Consortium grant as a user-oriented approach to maintain (and extend) health behavior changes.

These overarching aims were operationalized in three specific aims:

- Identify and codify the evidence base: What do we know about how people interact with PHRs? What does the evidence base tell us about PHR design?
- Identify key research questions for study: Two sets of research questions drove this aim, questions that relate usability to adoption and use; and questions about PHR features and usability. What are the primary variables that influence adoption and use of PHRs? More specifically, how is adoption and use influenced by usability? What aspects of PHR systems most strongly influence usability?
- Extend the evidence base: A preliminary literature review demonstrated that the evidence base for PHR usability was insufficient for a systematic review that would inform a usability guideline framework. Therefore, four usability investigations were conducted related to four usability questions. How do or would people use a PHR? What are the effects of graphical and textual displays for test results? For medication management? What are the effects of degree of screen complexity and level of interaction? **In sum, the focus was on grounding the guideline framework in an actual user needs assessment and in adding to the usability evidence for the important function of viewing and understanding information displayed in a PHR.**

Over the course of 18 months, the team met periodically to plan and discuss progress, conducted literature searches and examined PHR systems, designed special-purpose prototype PHR instances, and conducted four usability studies. Each of the usability studies was led by one of the investigators and included other faculty investigators and at least two graduate students. The culmination of these efforts yielded a framework for usability guidelines that balances the needs of consumers and heath care professionals.

Personal Health Record Usability Literature Environmental Scan.

In a recent white paper, Tang et al. (2006) describe desiderata for PHRs and some strategies for promoting adoption, but lament the lack of evidence for adoption, use, or economic models. Thus, while there is enormous attention given to the potential value of PHRs to help people better manage their health and participate with their health care providers in making good health care decisions, there is little evidence about usage or design. Few research studies of PHR usability were found, so it was impossible to do a classical systematic review. What we offer, instead, is an environmental scan.

To illustrate the dearth of PHR usability evidence, consider the results from two specific query sets submitted to PubMed Central: 'personal health record usability' (PHRU) and 'electronic medical record usability,' (EMRU). These queries yielded 93 and 74 results respectively, 66 of which overlap. Thus, two of the most common query phrases yielded a total of 101 unique records from 1987 to 2006 (note these date reflect the searches run in November, 2006 and five of the total were 2006 publications not in the original searches done September 2005). Of the retrieved articles for both queries, only eight focused on patients as users (Adams et al., 2004; Hassol et al., 2004; Kim & Johnson, 2004; Masys, et al., 2002; Tjora et al., 2005; Williams et al., 2004; Winkelman, 2004; Winkelman & Leonard, 2004; Wu et al., 2005), 44 focused on health care professionals as users, and the remainder focused on specific technical innovations, design related methods, or PHR/EMRs in general. Over the course of the project, variations on these queries were used in PubMed Central as well as in Google Scholar, citation chaining was used (following the citations in the pertinent papers found), and recommendations from members of the project team as well as others in the usability and health care fields were elicited. Studies are clustered into two groups: those that address feasibility or use of PHRs and those that address some specific usability aspect of PHRs.

The literature demonstrates that people are interested in using PHRs and that some consumers do use PHRs or MHRs in practice. 1421 patients who used a specific health care system responded to a survey about their experience with online communication and access to their medical health records (Hassol et al., 2004). Respondents found the system easy to use (78-85% on a 100 point scale) and were generally satisfied with the accuracy and understandability of their medical information. This study also illustrated some of the differences between patients and clinicians in that patients preferred email or in—person communication, whereas clinicians preferred telephone communication. Fowles et al. (2004) surveyed 3609 patients about interests in access to their medical records; 36% reported being very interested and 43% somewhat interested. Half wanted to examine their records online annually. Pyper et al. (2004) asked 100 patients to view their electronic health records for the first time according to a semi-structured guide through the records and then interviewed them afterwards. The majority of patients found the system easy to use. Patients wanted to correct information (nearly one-quarter found errors in their records) asked that technical medical terminology be explained, and were concerned with confidentiality of information. The important issue of record confidentiality is considered in the Personal Internetworked Notary and Guardian project that aims to allow individuals to secure their health records while selectively sharing them with health care providers (Mandl et. al., 2001; Riva et. al., 2001). However, there were no usability studies of confidentiality management found.

Ultimately, health outcomes will determine how useful it is to give patients access to their medical information. Garrido et al. (2005) used a cross-sectional statistical analysis of office visits in two large geographic regions over a two-year period and found that the number of office visits declined by 10% as online access to medical records was introduced. Neither laboratory services nor quality of care measures differed, thus suggesting that patient access to their medical records can improve clinical efficiency. Cimino et al. (2000) conducted a case study of patient usage of a web-based PHR system that had a wide range of features, including patient data entry. The authors report good usability and utility for the system. Another study by Cimino and his colleagues (2002) found that people varied in how often they examined their MHR records; their use was mainly to review laboratory results.

Some researchers have examined the effects of access to medical records for specific health conditions. Ross and his colleagues (Ross et al., 2004; Earnest et al., 2004) found that patients with congestive heart failure were more adherent to medical advice, although no differences were found on self-efficacy measures. They report that Cawsey et al. (2000) developed a system that provided customized, personalized cancer information for patients and found that patients preferred the personalization. Although this was not a medical health record study, the results on personalization may apply to PHR usability. Stroetmann et al. (2003) report preliminary results from a case study of five patients with end-stage renal disease who monitored their weight, blood pressure, pulse rate, and electrocardiogram at home. These patients wanted small subsets of data from the complex data available and want flexibility in how they view the data (graphs and tables, different time periods, single to multiple data sets).

Jerden and Weinehall (2004) reported on a survey of 418 patients who were given a personal book about their health and found that a quarter reported positive life style changes related to diet, exercise, and stress. In a similar study, Tobacman et al. (2004) gave 150 patients paper-based PHR systems; after six months, these patients entered good documentation for immunizations, allergies, medications, and surgeries. Athough these are not PHR studies, these and many other similar studies demonstrate that the act of systematically monitoring health behavior often has positive benefits and such benefits may accrue with PHR use as well.

These few studies illustrate the feasibility of people accessing medical information and provide some guidance to designers of PHR systems. Several studies focused more specifically on the usability of health information, although not all in a PHR context.

As part of their development of the Patient-Centered Access to Secure Systems Online (PCASSO) Masys et al. (2002) studied 68 clinicians (of 216 enrolled) and 26 patients (of 41 enrolled) who used the system. They found no security breeches and about 70% of clinicians and patients said that having records accessible on the Internet valuable. Clinicians were especially critical of the security complexity of logging into the system. Alonso (1998) reports on a user study that compared the LifeLines system Plaisant et al. (1998) that uses timelines to organize personal health information to tabular displays. Subject performed statistically significantly faster with LifeLines on time interval comparisons and multiple table lookups but not other tasks. The tabular condition yielded fewer errors, mainly when exact values were required. No statistically significant differences were found in user satisfaction. However, those who used the LifeLines performed statistically significantly better on an end of session recall test.

Nahm et al. (2994) studied how older adults use health web sites. Based on the results, they counseled designers to avoid small font sizes and too much information on screens, and to provide clear instructions. The important issue of people entering data into their PHRs was studied by Kim et al. (2004). They gave eleven patients with thyroid hormone preparation treatments a set of data entry tasks related to therapy goals, prescription information, and laboratory results and to use free form fields, pick lists, or radio button selections. Subjects' abilities to correctly enter data varied by the complexity of the task and that data entry in free form fields was problematic with respect to spelling and acronym use. They recommended providing structured data entry whenever possible.

PHR Systems.

The marketplace often drives innovation and PHR system development has been more active than usability research. In 2006, the Markle Foundation identified more than 167 different PHR products.[3] We examined those that were publicly available (More than 20 of the websites listed led to dead links). They range from full-featured systems available from specific health care provider or payer organizations (92 were from such organizations) to standalone products from small companies. Ninety-two were aimed at health care organizations and their members, 57 were aimed at general consumers and another 16 to consumers or health care providers. Two targeted consumers with specific diseases (cancer, diabetes). Less than one-quarter of these PHRs link to MHRs, and three-quarters of them are Internet based. An important contribution of this work by Markle is the categorization of 32 PHR functions into five classes: medical management functions such as medication tracking, medical history, etc. (11 functions), administrative management such as emergency contacts and bill paying (7 functions), other functions such as reminders, physician messaging, and data monitors (7 functions), security such as firewalls (4

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[3] Thanks to Josh Lemieux of the Markle Foundation for sharing this information.

functions), and privacy such as passwords (3 functions). Each of these functions will carry a usability burden and thus inform the usability guidelines framework.

The American Health Information Management Association (AHIMA) provides webpage links http://www.myphr.com/resources/) to PHR tools in three formats (Internet, software, paper) and two cost levels (free, for purchase). Of the 74 different products; 39 are strictly Internet-based for purchase and 11 are strictly Internet-based and free, 15 are standalone software for purchase and two are standalone software for free, five are paper-based for purchase and two are paper-based for free, six are available in two different formats for purchase, and one is available in all three formats for purchase. AHIMA also provides a paper-based health information form for adults (15 pages) and one for children (5 pages). The adult form has more than 600 fields to complete, some of which are repeating fields. In addition to reviewing many of the free systems, a small sample of commercial products was purchased for examination. All these systems must display enormous amounts of information and require scores of fields that users complete. Figure 1 shows a screen display for the ICER-2-Go main page user interface[4]. In addition to the system administration buttons near the bottom of the screen, each of the documentation tabs leads to a screen with scores of data fields. In the figure, the family information screen is shown and personal and contact data fields are provided. Including a photograph is a useful feature (especially if these can be saved over time) but does require knowledge of how to manage and import image data—a quick and easy step for experienced computer users but a significant challenge for novices. Clearly, using a PHR requires three substantial kinds of experience: computer experience (to understand basic interaction mechanisms such as using menus and tabs, entering data in forms, importing external files, and opening, saving, and backing up the application and data), health information experience with medical health concepts and terminology; and personal record keeping experience to recall or find the information needed to create the PHR records.

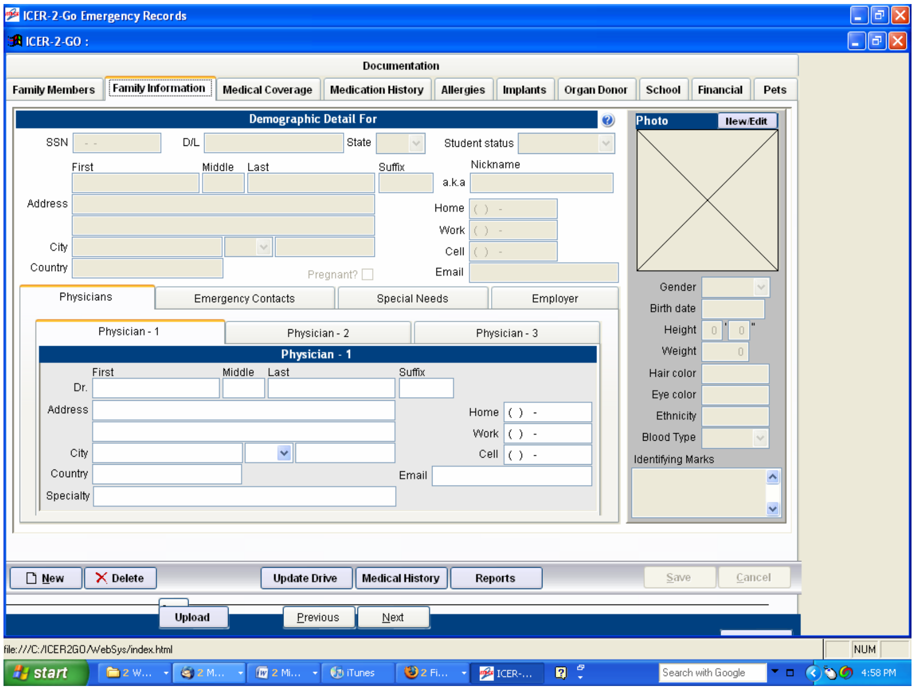

Figure 1. Screen display for ICER-2-Go main page

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[4] This is a screen display from one commercial product, ICER-2-Go. This is a copyrighted screen display from one of the systems we purchased for review. Including this particular screen display is not meant to be an endorsement or a critique of this particular system, but rather to illustrate the complexity of a typical PHR.

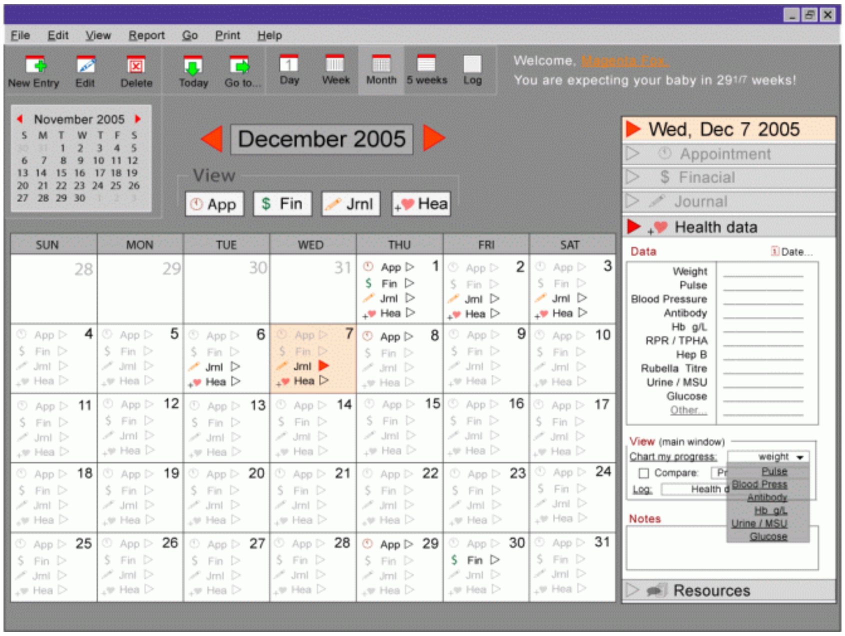
These analyses of existing PHR systems illustrate the complexity of PHR management and reinforce the need for attention to usability issues. Innovators and early adopters may ignore the frustration resulting from poor usability, but the majority will not readily adopt systems that are not easily usable without large and demonstrable benefits.

Prototyping

As we investigated the literature and planned our user studies, it was necessary to create mockup systems that could be used as stimuli in the user studies. These mockups are described in the papers forthcoming from the individual studies. Additionally, a set of alternative designs for a specific medical condition was created. Protoyping and mockups are important components of rapid prototyping in development efforts. However, creating such mockups is also useful to identify design issues and to prioritize variables that may influence usability. To this end, a set of mockups was created for a specific health condition, pregnancy (Choemprayong et al., 2006; Oh et al., 2006; Sheble et al, 2006; see http://sils.unc.edu/~songphan/wikiphr/index.php?title=Personal_Pregnancy_Health_Records:_Experimental_Interfaces for a report on the design rationale). This effort was part of a course project by three graduate students associated with the project who were interested in a health application that involved more than a single individual (a family) and that covered a specific time span and for which they has some personal experience. They thus chose pregnancy as the health condition. The work was supervised by the principal investigator.

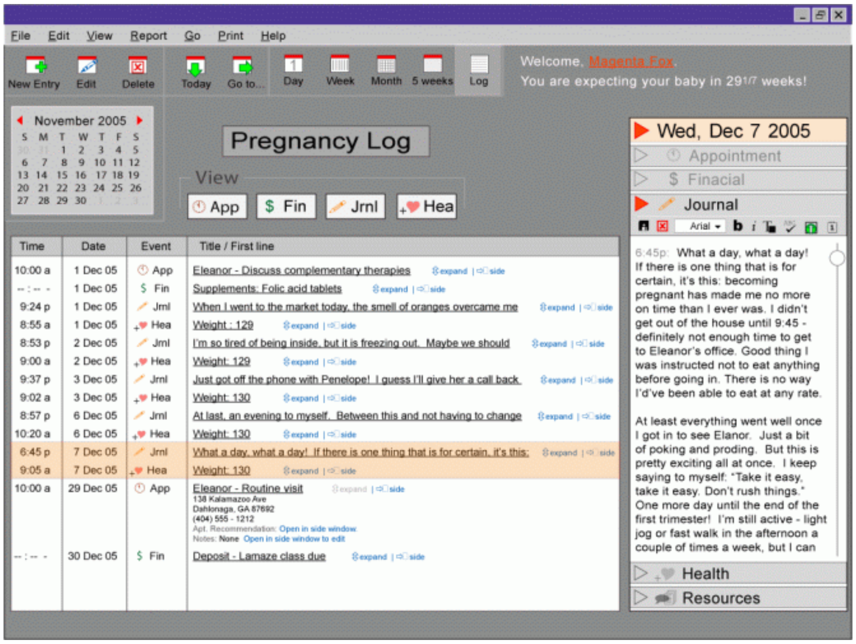
Examination of the pregnancy literature (e.g, Gibbins & Thomson, 2001; Hart et al., 2003; Jones et al., 2003; McKenzie & Carey, 2000; New Zealand Health Information Service, 2004; Travers & Downs, 2000) led the design team to focus on time as the primary organizer for five general functions: appointments, finances, journal or diary, health data, and information resources. Three alternative user interfaces were mocked up based on an analysis of key design variables, options, and design rationales. The design team focused on temporal organization scheme, navigation, and graphical display as three design variables. For temporal organization, the timeline and calendar were compared; for navigation, refocusing with tabs or slider bars and continuous zoom were compared; and color coding and graphical icons were included in each of the mockups. These were graphical mockups rather than actual systems. Nonetheless, the design process was the primary interest and the analysis and discussion that led to the mockups raised important usability issues.

Figure 2 depicts the flat calendar design that is a highly familiar organization for a time-based user interface. The advantage other than familiarity is that an entire month is available per screen with details for a given day (the focus) easily selectable and displayed on the right panel. One disadvantage of such designs is that most of the screen real estate is devoted to the month-long context. One possible alternative is to arrange the days in a temporal list rather than an array and such an alternative is shown in Figure 3.



Welcome, Magenta Fox.
You are expecting your baby in 29 1/7 weeks!

Figure 2. Flat Calendar Design



Welcome, Magenta Fox.
You are expecting your baby in 29 1/7 weeks!

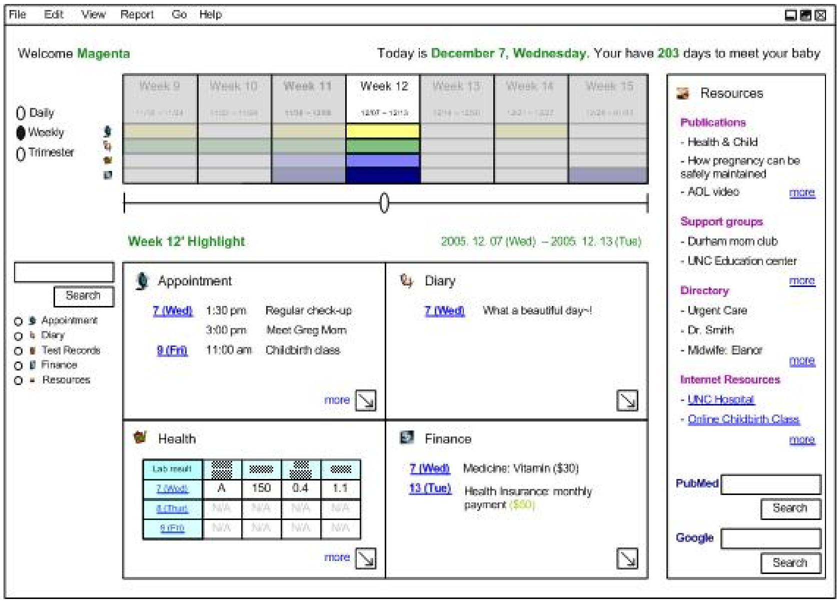
Time	Date	Event	Title / First line
10:00 a	1 Dec 05	App	Eleanor - Discuss complementary therapies expand | side
-- : -- -	1 Dec 05	$ Fin	Supplements: Folic acid tablets expand | side
9:24 p	1 Dec 05	Jrnl	When I went to the market today, the smell of oranges overcame me expand | side
8:55 a	1 Dec 05	Hea	Weight : 129 expand | side
8:53 p	2 Dec 05	Jrnl	I'm so tired of being inside, but it is freezing out. Maybe we should expand | side
9:00 a	2 Dec 05	Hea	Weight: 129 expand | side
9:37 p	3 Dec 05	Jrnl	Just got off the phone with Penelope! I guess I'll give her a call back. expand | side
9:02 a	3 Dec 05	Hea	Weight: 130 expand | side
8:57 p	6 Dec 05	Jrnl	At last, an evening to myself. Between this and not having to change expand | side
10:20 a	6 Dec 05	Hea	Weight: 130 expand | side
6:45 p	7 Dec 05	Jrnl	What a day, what a day! If there is one thing that is for certain, it's this: expand | side
9:05 a	7 Dec 05	Hea	Weight: 130 expand | side
10:00 a	29 Dec 05	App	Eleanor - Routine visit expand | side 138 Kalamazoo Ave Dahlonaga, GA 87692 (404) 555 - 1212 Apt. Recommendation: Open in side window. Notes: None Open in side window to edit
-- : -- -	30 Dec 05	$ Fin	Deposit - Lamaze class due expand | side

6:45p: What a day, what a day! If there is one thing that is for certain, it's this: becoming pregnant has made me no more on time than I ever was. I didn't get out of the house until 9:45 - definitely not enough time to get to Eleanor's office. Good thing I was instructed not to eat anything before going in. There is no way I'd've been able to eat at any rate.

At least everything went well once I got in to see Elanor. Just a bit of poking and proding. But this is pretty exciting all at once. I keep saying to myself: "Take it easy, take it easy. Don't rush things." One more day until the end of the first trimester! I'm still active - light jog or fast walk in the afternoon a couple of times a week, but I can

Figure 3. Day List Alternative Design.

We created an alternative mockup (Figure 4) to explore ways to maintain temporal context while displaying information for each of the five facets for a day on a single screen. In this design, a timeline that can be adjusted with a radio button tool is used for context; the remaining screen is allocated to the five information facets. This design provides much more information for a specific day at the cost of overall context and the familiarity of a calendar array.



Welcome Magenta

Today is December 7, Wednesday. Your have 203 days to meet your baby

Week 12' Highlight

2005. 12. 07 (Wed) – 2005. 12. 13 (Tue)

Appointment

7 (Wed)	1:30 pm	Regular check-up
	3:00 pm	Meet Greg Mom
9 (Fri)	11:00 am	Childbirth class

Diary

7 (Wed) What a beautiful day~!

Health

Lab result				
7 (Wed)	A	150	0.4	1.1
8 (Thur)	N/A	N/A	N/A	N/A
9 (Fri)	N/A	N/A	N/A	N/A

Finance

7 (Wed)	Medicine: Vitamin ($30)
13 (Tue)	Health Insurance: monthly payment ($50)

Resources

Publications
- Health & Child
- How pregnancy can be safely maintained
- AOL video

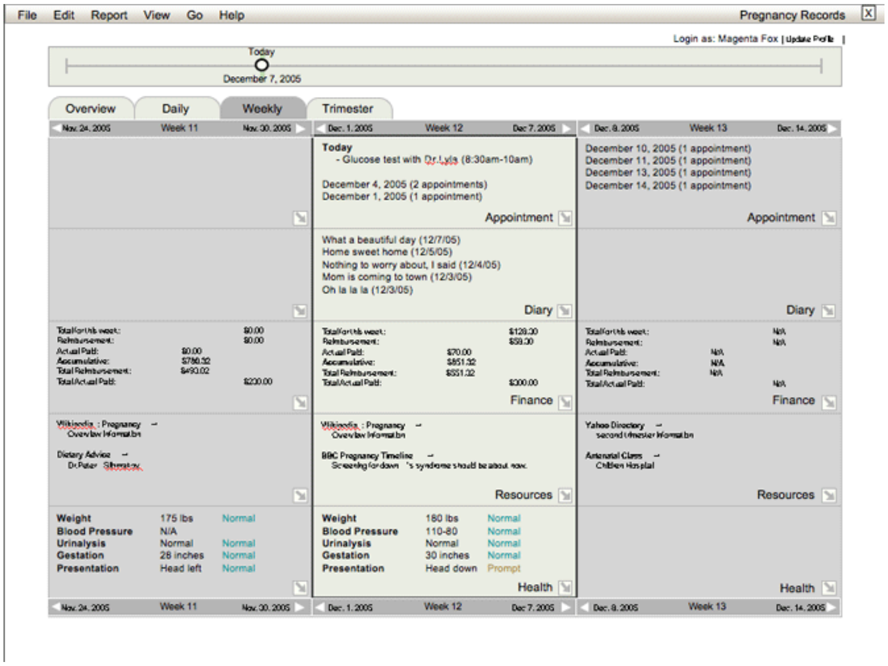
Support groups
- Durham mom club
- UNC Education center

Directory
- Urgent Care
- Dr. Smith
- Midwife: Elanor

Internet Resources
- UNC Hospital
- Online Childbirth Class

Figure 4. Multilayered Timeline

The final design aimed to provide different navigation for adjusting the timeline by adopting a continuous zooming metaphor. Figure 5 depicts this design with both tabs and a slider bar to expand the timeline period. The five facets are arrayed down the screen in the five regions for each day that is in focus with the previous and next days' information fitted to the time scale. This user interface provides the most flexibility to move within and across time; however, it is the least familiar navigation style.



Today
- Glucose test with Dr.Lyla (8:30am-10am)

December 4, 2005 (2 appointments)
December 1, 2005 (1 appointment)

December 10, 2005 (1 appointment)
December 11, 2005 (1 appointment)
December 13, 2005 (1 appointment)
December 14, 2005 (1 appointment)

What a beautiful day (12/7/05)
Home sweet home (12/5/05)
Nothing to worry about, I said (12/4/05)
Mom is coming to town (12/3/05)
Oh la la la (12/3/05)

	Week 11		Week 12		Week 13	
Total for this week:		$0.00		$128.30		N/A
Reimbursement:		$0.00		$58.30		N/A
Actual Paid:	$0.00		$70.00		N/A	
Accumulative:	$780.32		$851.32		N/A	
Total Reimbursement:	$490.02		$551.32		N/A	
Total Actual Paid:		$230.00		$300.00		N/A

Wikipedia : Pregnancy – Overview Information
Dietary Advice – Dr.Peter Silversky

Wikipedia : Pregnancy – Overview Information
BBC Pregnancy Timeline – Screening for down 's syndrome should be about now.

Yahoo Directory – second trimester information
Antenatal Class – Children Hospital

	Week 11		Week 12	
Weight	175 lbs	Normal	180 lbs	Normal
Blood Pressure	N/A		110-80	Normal
Urinalysis	Normal	Normal	Normal	Normal
Gestation	28 inches	Normal	30 inches	Normal
Presentation	Head left	Normal	Head down	Prompt

Figure 5. Layered Timeline

The design mockups were useful in identifying some of the layout issues for PHRs. Time as an organizing scheme for life events has been shown to be useful in empirical studies of personal health history designs (e.g., Alonso et al., 1998; Plaisant et al., 1998). These designs demonstrate the alternatives for leveraging time to organize health information in a relatively constrained case of pregnancy.

Four Original Studies

Study 1. Assessing the Needs of PHR Users

This study was intended to identify potential uses and concerns related to acceptance of PHRs. The aims were to examine the range of uses for which people might create and maintain personal health records, the types of data they might wish to keep in their personal health records, and the privacy and security issues that are most important to the users of PHRs. Preliminary results have been reported in a conference poster (Wildemuth et al., 2006), and a paper with full details is in preparation.

Forty-three semi-structured interviews explored frustrations with existing PHRs and the handling of medical records, the range of uses for which people would create and maintain PHRs, the types of data they would keep, and the privacy and security issues that are most important. Study participants were purposively recruited from four specific groups that are likely to be early adopters of PHRs: parents with young children, adults with chronic illnesses, adults caring for older parents, and older adults.

Most participants keep health records of some kind – primarily their health-related financial records. However, they had little confidence in their ability to find and use particular records when needed, and difficulties in sharing records between health provides often resulted in repetition of tests or medical procedures. As expected, participants would like their "ideal" PHR to include lab test results (tracked over time), medications (names and dosages, the doctors who prescribed the medicines, prescription numbers, refills, etc.), appointments with health care providers and the outcomes of those appointments. They would most like to view their PHR to prepare for upcoming physician visits and to monitor and investigate trends over time. In addition, they would like emergency health care providers to have access to their PHR. While most participants were comfortable with their care provider viewing and editing their PHRs, they were very wary of other people, not directly involved in their health care, having access to their PHRs (e.g., insurance companies or government agencies). While the participants were not universally comfortable with an external entity holding their records, most were uncomfortable with taking on the responsibility of holding and maintaining their records for themselves.

The results of this study identified a number of features that should be included in a PHR to ensure its acceptance by a broad range of potential users. While there is good consensus about the content of a PHR and the ways in which it might be used, there was little agreement about who should hold and maintain individual's records. If PHR systems are to be sustainable over the long term, we must also understand the level and type of commitment needed to maintain them.

Study 2. Visualizing Medical Test Results

This study aimed to identify optimal ways to present medical test information to patients electronically. Two computer-based experiments were conducted with 21 men and 85 women aged 30 to 83 (Brewer, Lillie, & Sheridan, in review). The first experiment examined the effects of varying the presentation format of medical test results, in tables or bar charts, using a between-subjects design. The second varied these presentation formats within-subjects. Both studies varied whether test results were normal or abnormal as well as the number of test results presented. Displays were evaluated in terms of usability (viewing time, recall of results, understanding and satisfaction) and health behavior (risk perception and behavioral intentions). Participants were given vignettes consisting of test results for different numbers of tests (i.e., single value such as a single result for a body mass index; or multiple values such as cholesterol or blood pressure readings along with filler test results) that varied with respect to being normal or abnormal.

Results for experiment one generally showed some benefits of the bar chart format with people often being faster and, under some conditions, more accurate than if they had viewed the table format. Also, participants' risk perceptions were strongly related to the degree of abnormality of test readings. The results for the second experiment showed similar speed and accuracy effects for bar charts, similar risk perception results, and also showed statistically significantly higher satisfaction with the bar chart presentations, likely due to the within-subjects design for experiment two where participants used both kinds of presentations.

We conclude, based on these results, that display presentation has strong effects on how people read and understand test results. Risk perceptions, an important factor in health behavior, are influenced by well-specified communication of test results.

Study 3. Use of Personal Medication Health Records by Older Adults

This study aimed to determine how adults aged 55 and older who take multiple medications manage information about their medications, with whom they share information about their medications, and what information they share, and what display formats are preferred for managing their medications (Hemminger et al, JAMIA, Jan 2007 submission).

Thirty people aged 55 or older who take five or more medications were recruited from retirement centers as participants and two sessions were conducted with each participant. In the first session, participants were asked a series of questions (e.g., names, dosage, frequency) about their medications, about how they shared their medication information, and asked to describe their current procedures for managing their medication regimens. Then, they completed a series of tests to evaluate how well they could recall their current or recent medication history information. In the second session, participants were shown three different computer-based visualization tools (calendar, bar chart, list) for personal medication history management. They received training using one tool, using a fictitious person's medication information to understand how the tool works. They then completed the same series of tests as in the first session on a second fictitious medication history. Finally, they were asked to rank the visualization tools and to compare and contrast them.

Participants wanted to manage medication information accurately and completely and to have it easily accessible (to them), and shareable with others (primarily health care staff and friends). On the other hand, they did not report a strong need for this facility based on the fact that they generally make little effort to systematically manage medication information or make it available to others. If information is available to them, they tended to prefer to have it in electronic form and to have it automatically ingested from the pharmacy. Overall performance and preferences showed that lists and bar chart visualization outperformed calendar presentation, and that all three computer based presentations were superior to the participants' standard methods (memory, lists, pill bottles). The best interface depended on what type of task, and no single interface was best for all tasks.

This study provided a user-grounded perspective on one important aspect of PHRs in that people who would theoretically have the most to gain from good medication management are somewhat ad hoc in their strategies and opinions about this aspect of PHRs. For widespread adoption, it will be important for PHR systems to quickly demonstrate usefulness beyond current practice, perhaps by showing overall improvements across multiple PHR data types and functionalities. Significant details regarding the pros and cons of the different visualization techniques, and effectiveness for the elderly were discovered. The overall guidelines that came out of the results include:

- Which visual interaction technique is best depends on the specific task
- The best computer based techniques were superior to human memory for recalling medication information details, both in accuracy and in speed.

- Information must be available from the Internet, so that it can be updated from pharmacies and health institutions, and available and shareable at multiple locations.
- Information must be displayable on different devices (web-based computers, PDAs, cellphones, printed paper, memory keys) to support access in different contexts.

Study 4. Interplay of Interactivity and Information Complexity on Cognitive, Affective, and Usability Responses to PHR Use

This study aimed to determine the interaction between interactivity, which tends to be a positive design goal, and information complexity on classic usability measures of task efficiency, effectiveness, and satisfaction (among others) for a mock PHR interface.

A 3x2 between-subjects, factorial experiment was conducted with two populations: young adults and older adults (over 50 years); 192 participants were recruited with 96 participants categorized as young adults and the remaining 96 classified as older adults. Interactivity, which depends on the degree of contingency or relatedness between message elements and implicitly gauges the level of user control (e.g., Sundar, Kalyanaraman, & Brown, 2003), was operationalized with a computer-based stimulus that offered 3 levels of interactive messages (low, medium, high). The second independent variable manipulated complexity of organization (e.g., Ariely, 2000) and was implemented at 2 levels (simple—with three modules of information; and, complex—with six modules of information). The efficacy of manipulation was assessed via a pretest. In addition, another pretest was employed to determine the actual information modules that were used to create stimulus materials. As outlined earlier in this report, the following six modules were deemed to be most useful in the context of user-centered PHRs: appointments/calendar, weekly journal/diary, financial information, information about specific health-related afflictions/diseases, prescriptions, and medical reports. In the complex condition, participants were exposed to all 6 modules, whereas in the simple condition, participants were exposed to 3 randomly-selected modules. Participants were informed that they would be exposed to a prototype PHR Website and that they should go through the site and answer some questions based on their browsing experience. At the end of the experiment, we assessed participants' perceptions of affect (e.g., attitudes toward the interface), cognition (e.g., recall and recognition of stimulus content), and usability (e.g., effectiveness and efficiency of task performance).

Interactivity and information complexity interacted in their effects on both cognitive and affective measures. These findings are qualified by statistically significant differences between the young and older adult populations. Older adults tended to spend significantly more time going through the PHR Website than did younger adults. Moreover, the differences between the two sample populations on dependent measures was mediated by participants' level of involvement—older participants were significantly more "involved" with the information featured on the site than were younger participants. In general, the benefits of providing interactive information (especially with increasing levels of information complexity) were more palpable among younger adults than with older participants, who expressed greater frustration and concern while navigating the interface. A paper with complete details is currently in preparation (Kalyanaraman, in preparation).

It appears that designers of PHR systems should be cognizant of the threshold at which interactivity can begin to exert negative effects, especially as the amount of health-related information to be processed increases. Importantly, these results also provide strong empirical validation to the misconception of "universalistic" interface design principles, and suggest that implementation of usability guidelines and heuristics can be maximized based on a clear understanding of the various user populations that are most likely to use PHR sites. One clear implication is that designers need to make a more concerted move toward the design of more "targeted" or "tailored" interfaces in the context of online PHR venues.

Usability Guidelines Framework

We present a framework for developing usability guidelines based on the literature review, examination of extant PHR systems, prototyping exercises, and completion of specific usability studies. There are a variety of usability and general design guidelines available for websites (e.g., Usability.Gov, http://usability.gov/ ; Nielsen's Alertbox, http://www.useit.com/alertbox/; MIT's website guidelines, http://web.mit.edu/is/usability/usability-guidelines.html), guidelines for accessibility (e.g., http://trace.wisc.edu/world/web/), and guidelines for different hardware platforms (e.g., Microsoft's Windows User Experience and more recent Vista interface guidelines, http://msdn.microsoft.com/library/default.asp?url=/library/en-us/UxGuide/UXGuide/Home.asp ; Apple's Macintosh Human Interface Guidelines, http://developer.apple.com/documentation/UserExperience/Conceptual/OSXHIGuidelines/XHIGIntro/chapter_1_section_1.html, and IBM's Ease of Use, http://www-03.ibm.com/easy/page/558). However, the focus here is on factors particularly important for or specific to PHRs. The investigations highlight three characteristics of PHRs that serve as organizers for the framework.

First, PHR systems are inherently complex. People's states of health and their illnesses are deeply complex. Additionally, health care involves many people (e.g., various clinicians and health care providers, family) and organizations (e.g., health insurance companies, hospitals, clinics). Health information originates from multiple sources, including clinicians, insurers, the individual record keeper, and various devices. Health information is personal and the physical and mental implications of health conditions strongly influence perceptions and behaviors. Thus, not only is there a large variety of possible information types and actors, but much of this information must be held in confidence, thereby requiring additional considerations for usage. This overall complexity for health information is far beyond the kinds of records (e.g., financial, social) that people typically manage in their lives. This complexity suggests a divide-and-conquer, layered strategy for usability.

Second, personal health information is pertinent to all people, regardless of their experiences with human health or technology, socio-economic conditions, age, and physical and mental conditions. Designing usable systems for everyone often leads to lowest common denominator solutions and eventually to strong standards for basic functionality. In the early stages of PHR development, the usability solution for the complexity and universality posed by PHR systems suggests customization paths for users. This is especially important with older users and people with specific chronic health conditions.

Third, personal health information is a life-long endeavor. The health record extends over many years and likely becomes even more important later in life when parents, spouses, and clinicians may not be available to inform decisions that benefit from past health history. The need for persistent records over time raises usability issues related to digital preservation and maintenance of effective archives.

Actual implementations may involve multiple products that work independently but can be easily integrated. Today, people use cell phones, PDAs, laptops, desktops, and central server devices for different tasks and needs and there is an increasing trend toward syncing these devices. Similar kinds of devices and services may emerge for health information so that mobile and stationary sensors and monitors collect data, support mobile inputs (e.g., voice annotations by patients or clinicians), and link these data streams with home computing and various clinical information systems. Currently, someone who uses an iPod shuffle for personal music when traveling and a full-sized iPod at work or home must exercise some effort to operate and sync these devices, let alone coordinate personal photos from cell phone, digital camera sources on personal storage (e.g., home computer) and online storage (e.g., Flickr). Likewise, the coordination of various PHR data streams and devices will require user effort that should be minimized through good interface design.

This triad of special challenges for PHRs is embedded in a framework that crosses PHR functionality categories with PHR data types and with more specific usability issues for PHRs.

The Usability.gov web usability guidelines aimed to be evidence based and were developed in a data-driven manner by identifying more than 500 guidelines from existing design guides, eliminating overlaps, finding examples for each from extant web pages, and then using a panel of usability design experts to complete card sorting techniques to cluster the guidelines. These clusters are the various 'chapters' of the guidelines, and the methodology of starting with published guidelines and using design professionals to classify those guidelines yields chapters that are mainly concerned with system components (e.g., hardware and software; the home page; headings, titles, and labels; links, and graphics, images, and multimedia) and design processes (e.g., design process and evaluation, optimizing the user experience; accessibility, page layout, text appearance; screen-based controls, writing web content, and usability testing) and a few on user functions (e.g., navigation, scrolling and paging, and search). Most important, the guidelines provide 'relative importance' and 'strength of evidence' ratings for each of the guidelines in the various chapters. The relative importance measures were determined through a survey of 36 design professionals and the strength of evidence ratings were determined through a survey of 13 usability professionals. This extraordinary effort was made possible by a substantial literature base and a dedicated team who worked over several years to develop and organize the guidelines.

Given the limited literature base and the more specific nature of personal health information, it is unlikely that the same data-driven procedures can be applied in the immediate future to develop usability guidelines for PHRs. The alternative is to use a more user-centered approach that begins with the kinds of functions and data that people will manage and add usability issues as a third contextualizing dimension. The three-dimensional scheme will yield specific combinations (e.g., check for data entry errors for the function 'enter data' for the data type 'advance directives') that may then spawn one or more guidelines. Rather than importance and strength of evidence for each cell, it may be possible to add evidence strength for some cells and to simply list options with corresponding design rationales for others. This would provide a framework that could evolve over time as more evidence becomes available to replace the design rationales. There are three general facets: PHR functionality (the kinds of actions people take with PHRs), PHR data types (the kinds of data people expect to have in PHRs), and usability issues especially pertinent to PHRs. Note that it is very likely that PHRs will not support all of the functions or data types in the near term; however, we aim to be comprehensive to better inform future designs.

PHR Functionality Dimension.
PHR User Activities are incorporated in a set of general functionality classes. Each class will have a variety of specific user-need based activities associated with it. Rather than specifying the many types of specific activities, the usability framework aims to cross each class with a primary data type and with general usability challenges. The PHR function classes are listed in Table 1 and brief explanations from a usability perspective follow.

Table 1. PHR Function Classes

- Enter data (direct or download)
- Find data
- Exchange data (send and receive, including local devices)
- View data
- Analyze and make sense of data
- Make decisions (information, tools)
- Communicate (appointments, referrals, email/social networks)
- Alerts and reminders

- Manage financial information
- Manage PHR as a system (e.g., security, preferences)

Finding health information includes a range of search functions both within the PHR system (e.g., finding one's weight three years ago in the PHR) and externally (e.g., finding the contact information for a physician during data entry, searching for background information on a disease, seeking an appropriate online support group).

Viewing (view is used in the general sense to include other sensory inputs such as hearing) and understanding what is viewed are crucial functions and most of the usability research for PHRs considers these functions. Thus, we might expect some evidence for the options in these cells.

In addition to viewing individual data points or trends within one data element over time, many users will want to conduct further analyses of their PHR data. For example, a user may want to understand how the occurrence of her severe headaches might be related to aspects of her diet, or a user may want to see if bouts of drowsiness are related to blood sugar levels. For such analyses, users will need to specify which data elements are to be analyzed over what time period and in what formats. For some analyses, users may be able to select from a number of useful displays to show results.

Entering data is perhaps the most under-estimated usability function for PHRs. Because there is so much data that might go into a PHR, especially during the initial phases of use, users may be easily overwhelmed by screen after screen of multi-field data entry forms. Shneiderman and Plaisant (2004) list 14 design guidelines for form fill ins, and these must be augmented in PHRs by cutting and pasting from other systems (e.g., clinicians' reports), automatically importing from other systems (e.g., biometric monitoring devices, clinician databases), and the possibility of other people (e.g., family, clinicians) directly entering data. The data entry usability issues for PHRs have not been studied and deserve serious attention by the usability community.

Communication is an important activity in health management. As seen in the literature review, health care professionals who study MHRs and PHRs identify patient-clinician communication as a key element of good health care. The recent Markle survey (2006a) found that patients (97%) want their clinicians to have access to their health information. Whether such basic communication capabilities (such as email) are embedded in the PHR system or people use their general email systems and cut and paste messages or attachments, this basic function must be made easy if people are to adopt and take advantage of PHRs. Beyond clinician communication, basic communication functions such as making appointments and refilling medications should become part of the PHR system and specific services should link seamlessly to the PHR. Additionally, activity on health forums or social networking services specific to health conditions may also be linked to PHRs. Each of these different kinds of communication activities involves specific systems and tools and usability will be greater if people are able to use familiar tools and easily add pertinent data to the PHR rather than expecting the PHR to support all these different communication activities.

Exchange data include exporting and importing data from various personal (e.g., monitors, different mobile and online systems) and external (e.g., public web spaces, clinics, pharmacies) stores either automatically or with direct user action. In either case, usability for configuration (in the automatic case) and access is an issue that could lead to user frustration or data record errors.

One important reason to store health information is to aid decision making. Initially, decision making will be based on first-hand discussions between patients and clinicians aided by the PHR. It is likely, however, that decision tools such as simple data mining techniques, automated exploratory trolls through the massive health literature using PHR data, or simulations based on PHR data will be introduced and people will use them before clinical visits. These more advanced functions will require significant user skill (both in using technology and understanding health concepts and relationships).

Alerts and reminders for appointments, medications, and other events can be helpful to people, however, they must be configured and managed and this adds yet another usability function for people to learn and use.

Keeping track of payments, co-payments, flexible account spending, insurance claim status, tax deductable expenses, and other financial events that involve multiple clinicians, hospitals, pharmacies, and other payees requires an accounting module in the PHR system. Ideally, this would be integrated with the payees' accounting systems and the users' individual checking/banking systems, however, it is likely that for the near term (10 years), these systems will remain connected on an ad hoc basis and thus people will be manually entering financial data into the PHR system. In some cases, distinct applications (e.g., a Quicken health module) might be used that are completely separate from the PHR system.

Managing the PHR system itself is another class of activity that promises usability challenges. System management is crucial since one cannot even get started without some basic administrative effort. The main challenge is that system management must be learned up front and then becomes routine. Extensive manuals that come with cell phones, cameras, and computers typically have a fast start section that helps users get started with basic functionality, with the expectation that they will acquire more advanced skills on an as needed basis. This training wheel (Carroll, 1990; Carroll & Carrithers, 1984) approach will likely help the usability of PHR administration functions as well.

PHR Data Dimension.

As the literature, PHR system analyses, and user needs assessment study demonstrate, there are a variety of types of data that people will include in their personal health records. Although some information will be common across all records (e.g., basic individual identification and health care professional contacts), the depth of completion will depend on individual preferences and health conditions. Additionally, people with specific health conditions may require substantial additional data elements specific to the disease or condition. Table 2 lists the kinds of data included in a typical PHR.

<u>Table 2. PHR Data Types</u>

- Personal Information (individual, family, health care providers and contact info, insurers, history, pets)
- Complaints (problem list)
- Clinical encounters
- Diagnoses
- Procedures (surgeries, treatments)
- Lab results
- Immunizations
- Allergies
- Medications
- Advance directives
- Nutrition and diet
- Exercise
- Personal commentaries
- Information resources (literature, glossaries, encyclopedias, webpages, listservs)
- Financial data

This list is not exhaustive and some of the data types are optional. The data types have been aggregated from examination of various PHR systems and the literature (e.g., AARP, 2006; Office of the National Coordinator for Health Information Technology, http://www.hhs.gov/healthit/chiinitiative.html; Tang et al., 2006). Additionally, the terminology used is not standardized and some actual data may be incorporated in different data categories (e.g., weight could be a personal information data element or an element of lab results in the case of different home monitors such as a networked bathroom scale automatically adding data to the PHR. Personal information can be very basic identifying information or include the entire medical history for a family, including genetic data. The intention of the framework is not to specify all data types but to include a reasonable set of data types that will support a variety of usability questions and guidelines.

PHR Usability Issues.
As noted above, in addition to the usual guidelines for general user interfaces and webpages, PHRs present three kinds of special challenges due to the complexity of health information, universal user population, and longitudinal scale of the information. These special challenges are strongly represented in the usability issues dimension of the framework. Unlike the other dimensions, the issues list is not mutually exclusive in that the issues are more subjective and may overlap. Table 3 lists a set of important usability issues

Table 3. PHR Usability Issues

- Issues related to complexity
    - Layout
    - Vocabulary
    - Number and nature of action options
- Issues related to interaction and control
    - Data input
    - Data output
    - System management
    - Data management
    - Help
- Issues related to user characteristics
    - Accessibility
    - Compatibility and flexibility

Good design can minimize effects of complexity on several fronts. Three of these fronts and obvious general guidelines to include follow. Because the screen constitutes the primary paradigm for presenting information in a digital form, a screen (page) tends to be the primary unit of attention, and good screen layout is crucial. Layouts that are well-organized and clearly labeled help minimize confusion. Vocabulary is especially important for health information systems because there are so many technical terms for diseases, medications, and procedures. Terminology should be clearly explained, with detailed information available on demand. The number of action options (e.g., buttons, menu items, hyperlinks) per screen also influences complexity, efforts should be made to present only important action options on any screen (e.g., providing optional actions in menus or preferences, or graying out non-active choices).

Issues of interaction and control strongly determine usability. Four classes of issues are included in the framework: input, output, managing both the system and the data, and help. Input takes many forms, including selecting an action, such as displaying a data record, downloading data from clinicians or the Internet, entering text or other kinds of data (e.g., a photo), and editing data. Input guidelines will likely include attention to error checking (e.g., spelling, viruses). Output is mainly in graphical form on screens of various sizes, although audio and tactile output may gain increased usage as smaller devices proliferate and telephony and computing continue to merge. Guidelines will surely address issues of readability. A PHR system, like any computer application, will require installation and configuration for the specific hardware/software/network platform, maintenance (e.g., software updates), security monitoring, and evolution of day-to-day work patterns. Data management beyond data entry and display includes regular backups and archives that must span decades. Given the complexity issues discussed above and the interaction issues listed here, good systems will provide different kinds of help and these help layers must themselves be usable.

Users vary across a host of physical, mental, and experiential characteristics. PHR systems must be particularly attentive to principles of universal access and the usability framework will surely include such guidelines. Additionally, the range of human characteristics argues for a range of user interfaces that maximize usefulness and usability. Thus, guidelines that address the difficult challenges of customization without adding complexity will also be included.

Conclusion

It is clear that PHR systems are gaining interest among the general population and that large and small companies beyond the health care industry (e.g., Microsoft, Intuit, Google) are developing PHR products and services. The consumer-centered thrust may become quite powerful and it is imperative that the window of opportunity for widespread PHR adoption be supported with easy-to-use and adopt systems. This project has used a multifaceted approach to generate a framework for PHR usability guidelines that aim to support PHR development and adoption. It has gathered information from the literature and from existing PHR systems, created mockups to get first-hand experience with usability design parameters, and conducted a set of usability studies. Future work should test the framework for completeness and granularity by populating the intersecting dimensions with guidelines based on evidence from the PHR literature and from web design.

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