

Prospective Personal Health Record Use Among Different User Groups: Results of a Multi-wave Study

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Abstract

Personal Health Records (PHRs) systems are a subject of intense interest in the move to improve health care through consumer empowerment. Yet, despite a surge of PHR offerings from a variety of providers, little research has been done to learn what prospective users want in a PHR and how they will use these systems. Because managing their personal health care information is a novel undertaking for most people, traditional technology adoption study methods are difficult to employ in researching PHRs. This paper reports on a user-centered design study that combines qualitative and quantitative approaches to investigate how health status may affect user needs for PHR. Preliminary analysis of the results indicates that users with disabilities differ from others in their PHR preferences. The results suggest that a particularly motivating factor for disabled individuals is the way in which a PHR will function when emergency services are required.

1. Introduction

A fundamental part of consumer empowerment through e-health is the implementation of personal health records systems (PHR)¹. By 2014, most Americans will have access to a PHR if present Federal goals are accomplished [1]. Yet there is relatively little research aimed at understanding what the target users for such systems will find useful, much less compelling.

¹ While there is no single authoritative definition for PHR, the term primarily refers to computer applications that allow individuals to view and interact with their own medical data.

The ultimate driver for PHR adoption has not been obvious, even as momentum coming from top-down initiatives has increased. The study described in this paper is among the first to investigate PHR user needs empirically. In this study, we examined the hypothesis that PHR user needs will vary based on health care status, e.g. whether a person is well, not well, or disabled. Using a triangulation approach combining qualitative and quantitative methods, we sought to probe some of the potential PHR user's most basic motivating factors: privacy, security, portability, and interoperability.

2. Personal Health Records Adoption: Challenges of Measurement

PHR adoption presents a somewhat unusual avenue of inquiry in that much of the grounding framework of the traditional Technology Acceptance Model [2] is difficult to apply [3]. One reason for this state of affairs is that PHR represents a novel task to nearly all users. This complicates any understanding of user preferences and behaviors. Task analysis and modeling is fundamental to user-centered design and to solving a core piece of the challenge of building a useful health care informatics infrastructure [4]. Acceptance becomes even more difficult to assess when users present with disabilities [5], like many of those who participated in this study.

Unlike other types of information systems, which model manual tasks with which users are familiar, PHR introduces a new kind of task, managing health information, which has not previously been performed by most people. Perceived ease of use is difficult (maybe impossible) to measure when prospective users have neither a physical nor mental model of the system being

investigated. Perceived usefulness, on the other hand, must be measured in terms of utility to the end user himself. Without a well-defined task, however, this is another dimension that presents serious challenges to measurement. To aid in understanding and defining the PHR task and to facilitate a movement toward more traditional models of IS adoption, we have taken a user-centered exploratory approach to our investigation of this type of system.

In order to begin to consider how and why individuals would adopt PHR, especially in light of the seeming lack of a compelling adoption driver, we examined the problem using a matrix of core user values and basic user attributes. The core values were derived from a list of 17 candidate values using a Delphi-like technique with a panel of experts [6]. Four candidate values topped the panel's list: privacy, security, portability, and interoperability. These are clearly distinct from value-maximizing constructs that apply to enterprise systems. They relate directly to the user's personal concerns about the impact of health information disclosure and about maintaining personal autonomy. Considered in terms of desired end states, the goal of PHR use is different from the kinds of goals promoted by most information systems. PHR is directed at issues of quality of life: living longer and healthier as personal objectives. By comparison, enterprise information systems only indirectly produce an enhanced quality of life as they are often focused on business and employee applications. Quality of life is, of course, directly affected by issues of health and disability. In studying prospective users, we have therefore segregated them along these dimensions, forming our evaluative matrix.

3. Research Methods

This study was conducted in two phases: qualitative in-depth interviews with three representative user groups, followed by a larger-scale quantitative survey, the aim being to foster a deeper understanding of potential PHR users by taking a triangulation approach. In exploring novel research area such as user-centered PHR design, knowledge must often be built from first principles, with little prior research paving the way in terms of research strategies and techniques. Further, there may be no pre-existing theoretical structure suggesting potentially productive hypotheses. In this situation, studies that combine qualitative and quantitative approaches are valuable. Carrying out an initial, exploratory qualitative study allows for the eliciting of issues and values important to the population of interest, while avoiding the pitfall of missing important data through top-down quantitative study design. Following up with a quantitative study allows survey questions to be devised based on what people actually report as the

issues of concern, rather than attempting to devise them intuitively.

In the qualitative phase, twenty-eight individual semi-structured interviews were conducted in three sessions during the second half of 2006: June 23-August 4, October 4-20, and December 14-15. Each of the sessions was targeted at one of the three main groups: Well, Unwell, and Disabled [7]. Each of these groups comprised 1/3 of the total subjects. Because of the sensitive nature of the qualitative interviews and the importance of a trust relationship with the interviewer, qualitative participants were not asked to provide detailed demographic data. Table 1 provides descriptive statistics that were obtained through basic interview questions and through observation.

Table 1 — Descriptive Statistics	N	%
Qualitative Interviews Total N=	26	
18-29	1	3.8%
30-39	5	19.2%
40-49	8	30.8%
50-59	4	15.4%
60-69	1	3.8%
70-79	7	26.9%
80-89	0	0.0%
90-99	2	7.7%
Sex		
Female	16	61.5%
Male	12	46.2%
Occupational Status		
Employed (full-time or part-time)	10	38.5%
Unemployed (seeking work or unable to work)	8	30.8%
Retired	10	38.5%
Health Status		
Well	19	73.1%
Unwell	9	34.6%
Disabled	13	50.0%
Non-Disabled	15	57.7%

A 40-question quantitative survey was conducted between April 2 and April 6, 2007. The sample was purposive, and, by design, not representative of the population as a whole. In order to include the desired level of response from disabled individuals, we elected to accept the analytical drawbacks associated with non-representative sampling. Initial groupings contained: 76 Well, 134 Unwell, 92 Disabled. A detailed analysis of

the three groups' PHR-related attitudes and behaviors, reported elsewhere, [8] indicates that the Well Disabled are more likely to share preferences with their Well peers than anyone else. Therefore, their responses have therefore been folded into the Well group. The same analysis indicated that the Unwell Nondisabled were distinct from the Unwell Disabled and these groups should be separate.

To dilute possible effects of demographic factors related to technology acceptance [9], wide demographic bands were sampled. Table 2 summarizes key demographics for the quantitative survey group.

Table 2 — Descriptive Statistics	N	%
Age		
18-19	3	1.4%
20-29	22	10.5%
30-39	27	12.9%
40-49	56	26.7%
50-59	74	35.2%
60-69	25	11.9%
70-79	3	1.4%
Sex		
Female	105	50.0%
Male	105	50.0%
Education		
Some high school or less	1	0.5%
High School Graduate or GED	44	21.0%
Some College, technical, or trade school	64	30.5%
Associate Degree	24	11.4%
College Degree	54	25.7%
Post Graduate Degree	23	11.0%
Household Income		
Less than \$25,000	29	13.8%
\$25,000 to \$49,000	62	29.5%
\$50,000 to \$74,999	49	23.3%
\$75,000 to \$99,999	38	18.1%
\$100,000 to \$124,999	14	6.7%
\$125,000 to \$149,999	6	2.9%
\$150,000 or more	6	2.9%
Prefer not to answer	6	2.9%
Occupational Status		
Employed (full-time or part-time)	127	60.5%
Unemployed (seeking / unable to work)	23	11.0%
Retired	24	11.4%

Other (student, not seeking work, etc)	36	17.1%
Self-Reported Health Status		
Excellent	24	11.4%
Very good	81	38.6%
Good	57	27.1%
Fair	34	16.2%
Poor	14	6.7%

The qualitative interviews broadly addressed the four key dimensions of interest (privacy, security, portability, and interoperability). The subjects' responses were analyzed preliminarily using content analysis. The initial goal of the qualitative portion of the study was to allow potential PHR users to surface issues, problems, and questions relevant to the role of personal health information management in their lives. From this exploratory starting point, we progressed to devising survey items for further analysis. The survey results were, in turn, interpreted in light of the qualitative interview responses, to reach a fuller and more textured understanding of the total study results than either approach alone would have been able to produce.

4. Summary Results

This initial study has produced findings that confirm our working hypothesis that there are observable differences among prospective PHR users, attributable to health status. It has also tended to disconfirm some common assumptions upon which present PHR policy has been based, for example assumptions about the value of privacy and security in a PHR vs. the value of technology.

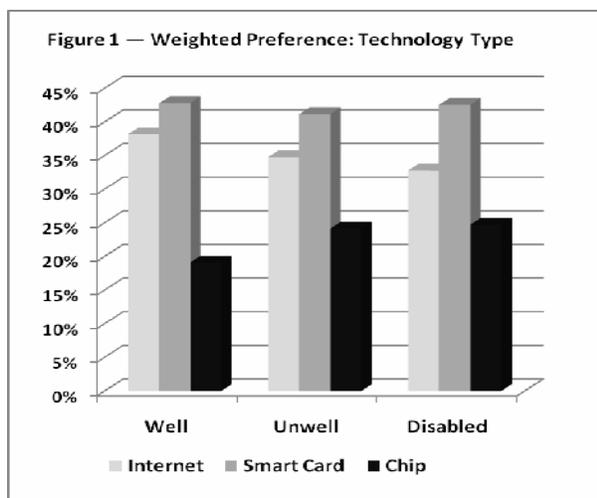
One theme emerged, which we had not anticipated: the importance of PHR in emergency circumstances, especially to individuals with disabilities. Within the qualitative interviews, a strong thread of concern over emergency situations was apparent. The level of concern expressed, for example in the passages quoted below, as well as the detailed descriptions of circumstances that engendered it set the disabled respondents, as a group, apart from both the well and unwell groups.

"I've had issues where I've woken up in the hospital...they couldn't find my family. I was in a coma for a few days. They had no idea of my history." Sarah O., Age 40, cerebral palsy.

"I have been in emergency situations where I was not capable of speaking and they needed to know everything right now." Nancy S., Age 46, traumatic brain injury.

4.1 Technology Preferences

Disabled respondents expressed a strong preference for a portable PHR solution, such as a “smart card².” Although PHR has been specifically defined as an Internet-based application, for example by The Markle Foundation [10], our survey group’s preferences do not support such a narrow conception. Survey respondents were asked to rank three types of potential PHR solutions: internet-based, smart card, and implantable microchip. Disabled people’s interest in an internet-based solution was much lower than that of the non-disabled. In the survey group as a whole, a portable “smart card” PHR is a strong preference, while the disabled were markedly less willing than others to consider an internet-based PHR, as shown in Figure 1, below.

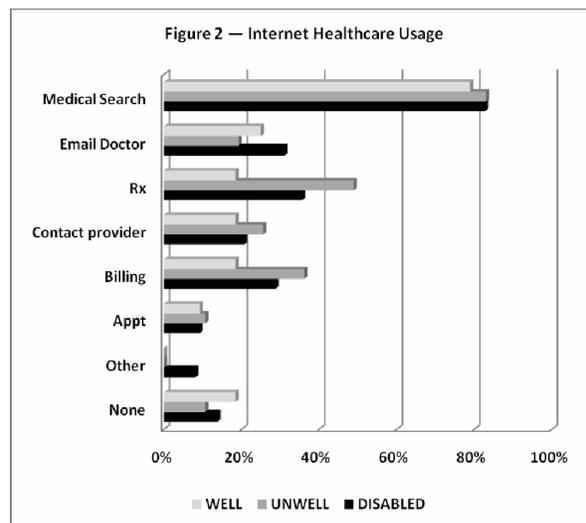


Note: Weighted preference % = $\frac{\sum(\text{item rank} \times \text{rank weight})}{\sum(\text{item weights})}$ for each respondent group.

Lest this difference be ascribed to a “digital divide”, we also asked respondents about their internet and general computing use, and specifically about how they use these in a healthcare context. Disabled individuals report that they are actually *more* active than others in using computers and the internet to perform medical-related tasks. Overall, medical-related computer use among the disabled is 19% higher than non-disabled well users and essentially the same as that of unwell users who are not disabled. This holds true across a variety of tasks, from searching for health information to viewing and paying medical bills, filling prescriptions, and communicating with their healthcare providers, as shown in Figure 2. In terms of computer

² “Smart card” is a generic term for a small portable device, usually about the size and shape of a credit card, which contains embedded circuitry, particularly programmable memory.

use for medical purposes, it is the well who use these resources the least. This is not entirely unexpected, since it is the well who arguably have the least reason to need such resources. Those who have the most need, the ill and the disabled, do take advantage of services available, which is a strong justification for attending to their needs in PHR design.



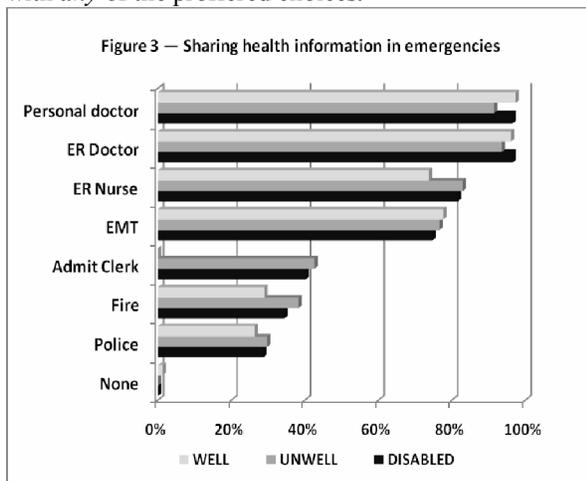
4.2 Privacy Preferences

In contrast to often-discussed concerns over health information privacy [11, 12], our survey group of disabled individuals appears to view emergency access to health information as a priority that may override some privacy issues. Figure 3 shows that they expressed a strong preference to have their medical information readily available to many types of service providers in emergencies. Nearly all of them (97%) wished to have their medical information available to their personal physicians and emergency room doctors. Most (75%) also wanted to have their information shared with emergency room nursing staff and with emergency medical techs. A sizable minority (30%) also desired to have their information given to hospital admittance staff and to police and firefighters who respond to the emergency. As one disabled respondent put it:

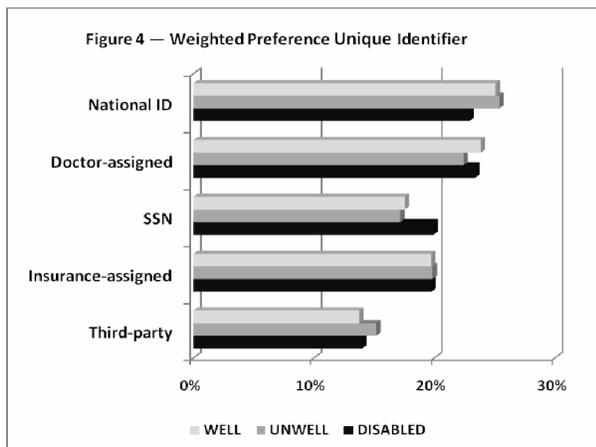
“I feel that if [I’m] going to a doctor and...need help or whatever I have nothing to hide...with all doctors I would want them to know. I’d want them to know me as a whole so they can treat me as a whole.” Stephanie, Age 31, spinal cord injury/quadriplegic.

By contrast, the well non-disabled respondents were less willing to have medical information shared in an emergency. Although most were willing to share the information with their doctors, fewer were willing to

trust this information to police or firefighters as first responders. Among the well who are non-disabled, some (1.32%) are unwilling to share their information with *any* of the proffered choices.



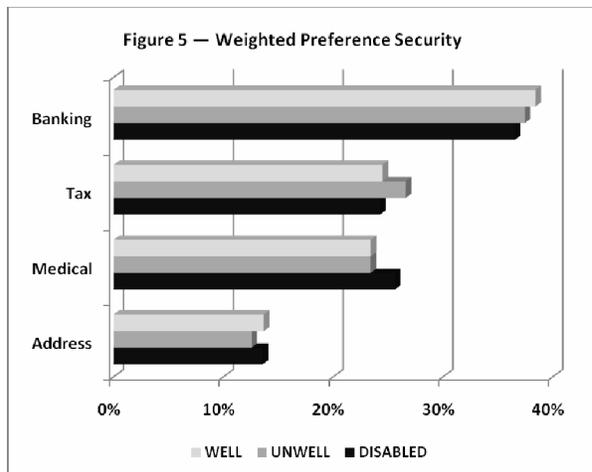
One proxy measure for general concerns over privacy is the use of a national medical identifier. Some privacy advocates oppose a national medical identifier, claiming widely-held privacy concerns among the general population [13]. This claim is not necessarily supported by our data, summarized in Figure 4, which show that a new, unique national-level identifier is the option around which there is the most consensus. Disabled individuals are more likely than other groups to opt to use their Social Security Number for this purpose



Note: $Weighted\ preference\ \% = \frac{\sum(item\ rank\ X\ rank\ weight)}{\sum(item\ weights)}$ for each respondent group.

However, considered in terms of public (national ID or SSN) vs. private assignment of a unique identifier, most people would prefer some type of privately administered number over a public, or nationwide, ID by a consistent margin of 57% to 43% across all three study groups.

Emergency or not, privacy and security of personal health information are both issues of importance to all, but the disabled vary somewhat from the general population in their preferences. Most people, regardless of disability status, say they are much more concerned about the security of their personal financial information than that of their medical data, as Figure 5 shows. People with disabilities differ in that they are slightly less concerned about banking and tax information security and somewhat more concerned than nondisabled people about their medical information.



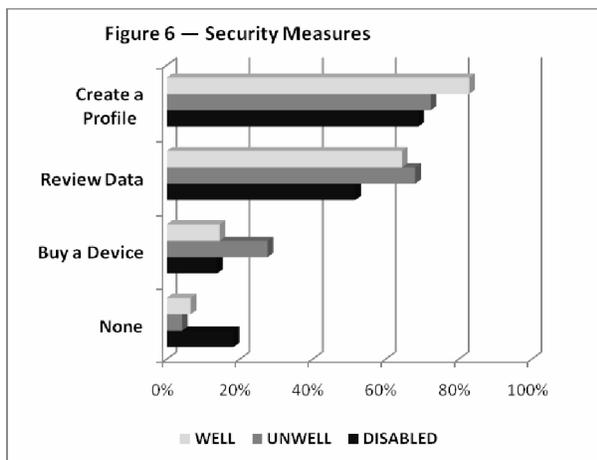
Note: $Weighted\ preference\ \% = \frac{\sum(item\ rank\ X\ rank\ weight)}{\sum(item\ weights)}$ for each respondent group.

Asked to choose between a high degree of protection for medical information vs. a trade-off approach that offsets information access against privacy protection, there was little difference between the disabled and non-disabled groups. Just under 60% of both groups favored the statement “The privacy of my medical information is very important and I want it protected at all times” while approximately a third of both groups chose “I want to balance the privacy of personal medical information with my health needs.” A small but interesting minority (10.5%) of respondents agreed with the statement “The privacy of my personal medical information is of no great importance.” On this, people with disabilities were less likely to agree (8.6% vs. 12.8%).

4.3 Security Preferences

Concern for information privacy and the willingness to take proactive steps to protect it do not necessarily coincide. Although most people, whatever their health status, express a concern for keeping their medical information private to a fairly high degree, making the investment in personally providing that protection is another matter.

Survey respondents were presented with four options for managing their PHR security: creating a profile that sets access permissions, reviewing their information to examine it for errors or unauthorized use, purchasing a device or service to secure their information, or doing none of these. As Figure 6 illustrates, there is a substantial difference between disabled individuals and others when it comes to securing information. Disabled individuals are generally much less interested in actively managing their information security. The disabled group opted out of security measures altogether more than twice as often (18.4% vs. 6.6%) as the well group, and more than 4 times as often as the unwell group (4.3%).

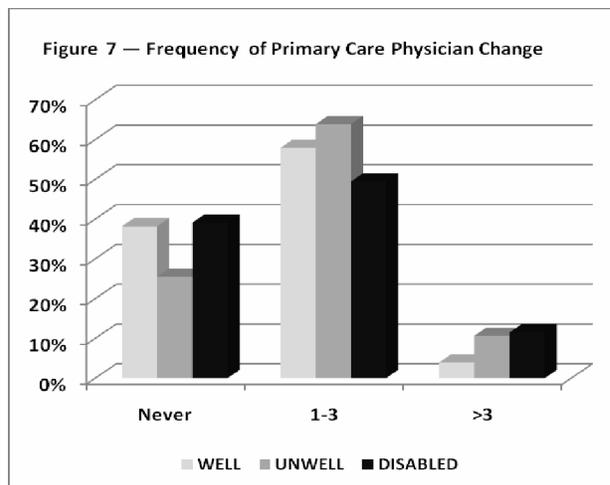


The three active security options include two no- or low-cost options and one with a definite cost attached. It is noteworthy that only the unwell group expressed more than a passing willingness to make an investment in security. More than a quarter would do so, compared to less than 15% in the other two groups.

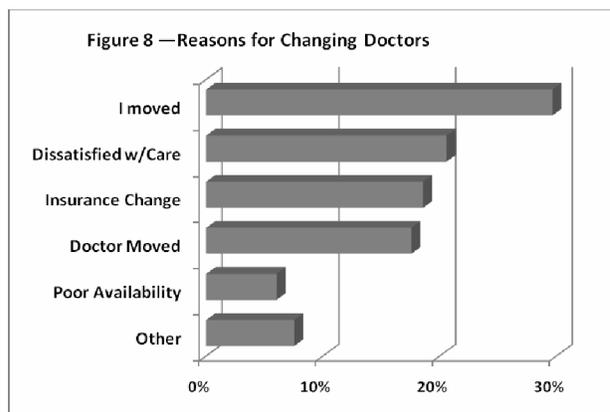
4.4 Portability Preferences

It is commonly accepted that Americans in general tend to be mobile both geographically and occupationally. Since medical care is always location-specific and often linked to employer, portability of medical information is cited as a concern by many. The leading discussants of PHR architectures typically make portability a high priority feature [14]. Yet recent demographic research on mobility shows a different picture. In exploring its impact on the future of elder care, Wolf and Longino found in examining Census Bureau data that mobility among Americans has steadily declined since the 1950s with the largest declines occurring among 20 to 29-year-olds [15]. Interstate moves, those most likely to enforce medical provider changes, are a relatively rare occurrence, with fewer than 5% of the population one year of age and older moving state-to-state in any

given year. Contrary to popular belief, today's Americans are more likely to live near their birthplaces than were their 19th-century predecessors [16]. The results of our study indirectly confirm this claim. Our survey respondents were asked how many times and for what reasons they have changed doctors in the previous 10 years. As shown in Figure 7, over 91% have changed doctors three times or less. Nearly 36% had never changed doctors, while only 8.6% had changed doctors more than three times.



Nevertheless, when our respondents did change doctors, the individual moving was cited as the top reason for doing so, as seen in Figure 8.



4.5 Interoperability Preferences

Interoperability refers here to the capacity for different PHR systems to communicate with one another, connecting physicians and other health care providers in a shared information network. This factor can be expressed in different degrees and it is a fundamental component of PHR system architecture. Our subjects were asked to rate the level of interoperability they would prefer in their PHRs. The choices varied from

the most restrictive, in which medical information is shared only among providers with whom the patient has a contractual (insurance) arrangement, to least restrictive, in which medical information can be accessed by any licensed health care provider.

Responses here were consistent regardless of health status. The top preference was to have information shared only within one's own healthcare network, i.e. the most restrictive model. The second choice was to permit data sharing among the patient's personal providers, regardless of whether those providers belong to his or her insurance network. Ranking third was sharing among all physicians provided they are licensed and ranked fourth was the option to allow any licensed healthcare professional access.

More than one of the qualitative interview subjects expressed the idea that not all of the care providers they see necessarily need to know everything about their medical histories. In particular, some were concerned that certain aspects of their health histories could be used to negative effect in their relations with their care providers. This concern may partially account for what appears to be a lower receptivity to interoperable PHRs than might otherwise be expected.

"[I]f there is anything to do with mental health in the picture, I would rather that not be visible to anybody unless I specifically gave permission ...For an emergency situation, they should be able to see everything...except mental health." Avra E., Age 52, Well.

"[I]f a woman has had an abortion, that's nobody's business except for the...provider and the insurer. I don't think it's anybody else's information...unless you choose to reveal that." Donna A., Age 77, Mild chronic illness

These results suggest that unlimited interoperability may not be a top priority among prospective PHR users. Asked to weigh the relative importance of interoperability against other preferences, including technology type, PHR provider, and medical identification scheme, the quantitative survey respondents rated interoperability and portability factors as least important.

Adaptive Conjoint Analysis (ACA) [17] was performed on six of the general survey questions. ACA is a market research technique designed to determine the optimal features of projected, as yet undeveloped products or services. The premise of ACA is that every product and service has multiple components, each with a different value to the consumer (utility value), and that individual values for these utilities can be quantified, summed, and compared. ACA data collection surveys combine respondent-selected importance ratings with pair-wise trade-off tasks. Respondents assign explicit importance ratings to features or functions, and these are followed

by trade-off tasks which include only those attributes and levels the respondent has rated as most important [18, 19]. A proprietary algorithm is used to calculate utility values, which indicate the perceived value of the feature and the sensitivity of consumer preferences to differences in product features. Here, the ACA results showed system type was valued at 81, provider at 57 and identification scheme at 56, while interoperability and portability were assigned much lower utility values of 46.

5. Discussion

These results tend to support two general conclusions: (1) there are observable differences between disabled and nondisabled users when considering PHR functions, and (2) there are specific rationales underlying the PHR preferences of both disabled and nondisabled user groups.

The ability to have immediate access to personal medical information in an emergency seems to be a defining issue for disabled individuals in terms of their relationship to personal health records. While several nondisabled respondents stated that they had thought about how their information would be accessed in an emergency, only the disabled respondents described incidents where access to personal medical data rose to the level of a life or death issue. This concern over emergency access is consistent with disabled individuals' overall higher level of emergency room utilization. Many permanently disabled individuals receive their medical care through Medicaid-funded public programs. Emergency room utilization studies among Medicaid recipients support the finding of higher ER usage among the disabled. While one group of all Medicaid recipient types had an average 33% ER utilization rate [20]³, a separate study found that recipients of Aged, Blind, and Disabled assistance had four times as many ER visits as other Medicaid beneficiary categories [21].

Personal and anecdotal experience with emergency services, as well as familiarity with the capabilities and limitations of the Internet as a service provision platform, may well combine to give disabled individuals a uniquely well-informed perspective on their PHR needs.

In general, disabled respondents in our study evinced less confidence in the Internet than did the nondisabled.

"I don't know about the Internet. That leaves a lot of people out." Janet K., Age 56, spinal cord injury

³ 329.4 visits per thousand, however ER utilization is unevenly distributed among population groups.

*"[O]n the internet there's not much privacy."
Christine M., Age 32, cerebral palsy*

"I think the accessibility of [the Internet] is great. I think it works better than most other systems." Nathan B., Age 36, Well

"I think the web is here to stay, so there will be... a web-based browser kind of [PHR]" Nicole G., Age 29, Well

While we did not collect quantitative data specifically relating to *why* disabled people are less sure about using the Internet for PHR, the distinction between this group and the nondisabled group in terms of preference for a portable smart card and a disinclination for the Internet is clear. It may be the case that the disabled, having more experience with limitations on their choices, are better able to imagine the limitations of a system that has greater restrictions on its portability and accessibility, both of which are more characteristic of the Internet than of a portable self-contained device. Another possibility is that the disabled people we spoke with are more familiar than others with the range of barriers to Internet usage among the disabled population as a whole.

Given the weight of preference regarding technology choice among both the disabled and other groups, it seems prudent to take this factor into account in making PHR design decisions. In particular, policy statements that assume an Internet delivery platform for PHR may need to be reviewed with the goal of expanding the end users' options. While there are many marketplace offerings that already implement a portable approach, even AHIMA's comprehensive list of PHR vendors and products does not contain a category for this solution type [22].

As noted above, privacy advocates have been successful in bringing a halt to any plans to implement a unique medical identifier at the national level. This movement has not necessarily been based on empirical evidence, but seems to be primarily an ideological stance adopted by a vocal minority. Our data indicate that this policy, and system design decisions based upon it, may bear re-examination as well. As others have pointed out, banning the notion of a unique medical identifier brings with it at least as many potential privacy problems as it purports to eliminate [23]. Supporting the notion that some type of national-level identifier is desirable, especially among the disabled, we find that they are more willing than others to consider allowing Social Security number to serve that role.

Finally, despite an apparently common assumption that people are very concerned with information security and the risks posed by exposure of their personal

data, our study finds that individuals are relatively less concerned about the ramifications of this with regard to health data than financial data. Disabled individuals differ on security in that they are even less willing than others to take proactive steps to secure their medical information. Design decisions based on the assumption that all PHR users desire extremely high security, and especially an assumption that people are willing to pay for this, may be less well-founded than previously thought.

6. Conclusion

As one of the first empirical studies of prospective PHR disability users, this analysis has revealed a view that may be at odds with the one held both by policy makers and by system developers. Although user-centered design normally cautions against a technology-first approach, when that approach is backed by expressed user preferences, it must be considered seriously. In the case of PHR, a thorough examination of user preferences would help to test our preliminary findings and further clarify user preferences. More research, especially studies based upon user exposure to PHR prototypes, would be valuable in filling in a more detailed portrait of the prospective PHR user.

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