The views and expectations of young healthy adults about using an online personal health record

Quynh Nguyen
Department of Family Medicine
McGill University, Montreal
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ABSTRACT [ENGLISH]

BACKGROUND: Personal health records (PHRs) are tools that allow individuals to access, share and manage their health information online. PHRs have received considerable interest and investment in recent years, because they are thought to have the potential to promote patient self-management and greater involvement in their own care. Despite apparent public interest and a proliferation of available options, adoption rates remain low. There is a gap in our understanding as to why people are choosing to use or not use PHRs, and what different populations of users might want from such a tool. In particular, young adults could be a potential group to target with preventative strategies using a PHR, since technology is much more integrated in their everyday life.

OBJECTIVE: This qualitative descriptive study therefore aimed to explore the views and expectations of young healthy adults about using an online personal health record.

METHODS: Four focus groups were conducted with a total of 29 participants (18-34 years old) from a community setting in Montreal, Canada. Interviews were transcribed and analyzed with inductive thematic analysis.

RESULTS: With respect to how young adults viewed PHRs, three broad themes were identified: perceived advantages to using a PHR; future PHR users; and concerns about PHRs. In terms of what they themselves expected from using a PHR, different themes were elaborated: characteristics of an "ideal" PHR; using the PHR for preventative health; taking more control over their health; and making the PHR worthwhile. A conceptual framework of factors influencing expectations of PHR use in this population is proposed.

CONCLUSION: The findings suggest that what young adults perceive as benefits of a PHR may not be the same things that motivate them to actually use a PHR. The results emphasize the fact that more research is needed to understand the expectations and anticipated use of different populations in designing a patient-centered tool. The proposed framework can be used as a basis and tested in future research on PHR adoption.

ABSTRACT [FRENCH]

CONTEXTE: Les dossiers de santé personnels (DSP) sont des outils qui permettent aux individus d'accéder, de partager et de gérer l'information sur leur santé en ligne. Ils ont obtenu beaucoup d'intérêt et des investissements considérables ces dernières années puisqu'on considère que les DSP ont le potentiel de promouvoir une plus grande implication des patients dans la gestion de leurs propres soins. Malgré l'intérêt public apparent et une prolifération des options, les taux d'adoption des DSP restent faibles. Notre compréhension des raisons pour lesquelles les gens choisissent d'utiliser ou non les DSP et de ce que les différentes populations d'utilisateurs pourraient vouloir d'un tel outil est limitée. En particulier, les jeunes adultes pourraient être un bon groupe à cibler en ce qui concerne les possibilités de prévention avec un DSP puisque la technologie est beaucoup plus intégrée dans leur vie quotidienne.

OBJECTIF: Cette étude qualitative descriptive vise donc à explorer les points de vue et les attentes des jeunes adultes en bonne santé à propos de l'utilisation d'un dossier de santé personnel.

METHODES: Quatre tables rondes ont été menées avec un total de 29 participants (18-34 ans) dans un milieu communautaire de Montréal, au Canada. Les entrevues ont été transcrites et ensuite analysées avec la méthode d'analyse thématique inductive.

RÉSULTATS: En ce qui concerne ce que les jeunes adultes pensent à propos des DSP, trois grands thèmes ont été identifiés: les avantages perçus, les futurs utilisateurs et les préoccupations au sujet des DSP. En terme de ce qu'eux-mêmes attendaient d'un DSP, différents thèmes ont été élaborés: les caractéristiques d'un DSP «idéal»; la contribution des DSP à la santé préventive en prenant plus de contrôle sur leur santé, et l'aspect pratique des DSP. Un cadre conceptuel des facteurs ayant une influence sur les attentes des participants à propos des DSP est proposé.

CONCLUSION: Les résultats suggèrent que ce que les jeunes adultes perçoivent comme avantages d'un DSP ne sont pas les mêmes choses qui les motivent à se servir d'une PHR. Cela souligne l'importance de comprendre

l'utilisation prévue et les attentes des populations d'utilisateurs spécifiques dans la conception d'un outil centré sur le patient. Le cadre proposé peut constituer une base pour de plus amples recherches sur l'adoption des DSP.

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INTRODUCTION

This thesis addresses the complex issue of adoption of online personal health records. Information technology is taking on an increasingly important role in attempts to improve and modernize the healthcare system and address current healthcare challenges, both in Canada and abroad.[1-4] With surging healthcare costs, an aging population, and the rise of chronic disease, there is an even greater need to find solutions to deliver accessible, high-quality care from within already overextended resources. It is thought that health information technology (HIT) can address some of these issues in part by facilitating movement towards a more patient-centered,[5-7] integrated and collaborative approach to healthcare.[1,8,9] Among the many different HIT applications currently available, systems such as the electronic medical record and personal health record are thought to have the potential to improve healthcare quality and safety, increase efficiency, facilitate communication between patients and healthcare providers, and promote the involvement of patients in their own care.[1,8-12]

In particular, the personal health record (PHR) is a trend in healthcare that has generated considerable interest and investment in recent years. [3,13,14] Though the concept of a PHR has emerged over the past decade, the idea of keeping personal copies of medical documents itself is not new.[15-17] The term "PHR" has been used to mean different things and continues to evolve, but one commonly accepted definition of a PHR by the Markle Foundation (2003) is "an electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure and confidential environment."[18] The PHR is considered distinct from the electronic medical record or electronic health record (EMR/EHR), which is a computerized version of an individual's health record generated and maintained within an institution, such as a hospital, integrated delivery network, clinic, or physician's office;[11] however, these two systems *can* be connected. While EMRs consist of health information that is aimed to be used by the healthcare provider or institution, PHRs are intended to fulfill the health information needs of the

patient. As a result, they are seen as *patient-initiated* tools and are widely regarded as having the potential to promote patient self-management and involvement in their own care.[4,5,18-20]

In this respect, current interest in PHRs may be the result of converging trends: (1) the movement towards greater patient involvement, shared decision making and patient-centered care;[5,21,22] and (2) the increasing demand of patients and health consumers to have access to health information. Individuals are increasingly being seen as consumers and stakeholders in their own health, and evidence suggests that having patients engage in their healthcare can result in better quality of care through improved communication with their provider, participation in shared decision-making, and increased sense of responsibility for their own health.[23,24] At the same time, patients are turning to the Internet to seek out and exchange information to manage their own health.[25,26] In 2009, 70% of Canadians 16 or older, or an estimated 18.9 million people, went online to search for medical or health related information.[27] This represents an enormous upsurge from a decade earlier (15.6% of households in 1999) and this trend in health information-seeking behaviour continues to rise.[28,29] Thus the interest in PHRs represents an intersection of these trends, and it is believed that "using a PHR will help people make better health decisions and improve quality of care by allowing them to access and use information needed to communicate effectively with others about their healthcare."[30] Additionally, since PHRs could improve the efficiency of administrative and clinical process within healthcare, it has been argued that successful PHR implementation and adoption could thus translate to significant savings in healthcare costs.[23,31]

As a result, there is presently widespread interest and activity in PHRs, both in the private and public domain. Much of the enthusiasm surrounding PHRs is related to their *anticipated* value and benefits to consumers and the healthcare system.[4,15,32] Despite the proliferation of available options, as well as apparent public interest in having PHRs, adoption rates remain low.[33] There is a gap in our

understanding as to why people are choosing to use or not use PHRs. PHRs differ from other forms of HIT in the sense they are patient-driven and therefore require a larger involvement and motivation on the part of the user as opposed to the healthcare provider and/or system. It may be that the discrepancy between apparent interest and actual adoption of PHRs may lie in the fact that patient-user views have not adequately been considered and incorporated when designing what is ultimately intended to be a patient-centered tool.[34] For example, integrated and tethered PHRs are frequently adapted from existing provider EMRs, and have not necessarily been designed with patient use in mind. Adoption of new innovations and technologies is a complex phenomenon and subject to many influences. The assumption underlying this proposed research is the notion that the successful adoption of PHRs requires the perception of inherent value as well as a fit between the technology and the wants, needs and characteristics of the end-user.[34,35] Therefore, it is important that we have a better understanding of what potential users, and *specific* groups of users, want and expect from this technology.

Young adults, in particular, are an understudied group that represents a potential target for prevention and/or early intervention strategies with PHRs. Existing PHR studies have generally looked at the older and chronic disease population, largely where PHRs were offered through patients' healthcare providers.[34,36-42] Furthermore, existing research has mainly focused on the use of PHRs for managing existing health conditions, but little consideration has been given to the potential role of PHRs in prevention strategies.[8] However, as espoused at the 2005 National Health Information Infrastructure Hearings, "personal health records are a unique mechanism to engage individuals at different life stages, in their own health, and a novel platform for prevention activities that could include information, recommendations and attitudinal and behavioural messages."[43] Though most young adults are still healthy and do not have any major health issues, this population does not necessarily access healthcare services on a regular basis and may face challenges in terms of continuity of care. Over half (54.2%) of

adults aged 20-34 in Montreal (2009) do not have a regular physician.[44] Moving and transitioning to adult care can likewise contribute to gaps in care in this population. PHRs could thus could represent a useful tool to facilitate access and information to a hard-to-reach population at a point where encouraging greater sense of involvement and effective ownership over their own health could translate to better health outcomes in the future.[2]

Moreover, younger adults may in fact be more likely to adopt PHRs in the future, as traditionally identified barriers such as computer literacy and privacy concerns may not apply to the same extent as other groups. According to Statistics Canada, over three-quarters (80.3%) of Canadians accessed the Internet in 2009, and individuals between the ages of 16–34 overwhelmingly represent the largest segment of Internet users (96.5%) and use it on a more frequent basis.[45] This population has come of age in a world of the Internet and is more apt to have information and communication technologies integrated into all aspects of their everyday life. Additionally, social networking tools such as Facebook and Twitter and online sites such as Google and Wikipedia may have changed previously held views of privacy, information-sharing, and data ownership. For example, one-fifth (20%) of home Internet users reported contributing content by posting images, writing blogs, or participating in discussion groups; of these people, over one-half were under the age of 30.[45] The way this group interacts and their expectations of technology may be fundamentally different from other generations. However, little is known about what issues may affect PHR adoption in this population, and it will be important to identify and understand these issues in order to achieve successful adoption. Therefore, the objective of this study is to explore and describe what the views and expectations of online PHRs in young healthy adults. Specifically, my research questions are:

1. What are the *views* of young healthy adults about online personal health records?
2. What do young healthy adults *expect* from using online personal health records?

LITERATURE REVIEW

With these research questions in mind, this literature review will first examine personal health records (PHRs) and the current state of development and then will proceed to address what is known about the issues surrounding adoption of online PHRs with a specific focus on the individual-level issues.

The Current State of Personal Health Records

As previously mentioned, the concept of a PHR has evolved considerably over the past decade. From early standalone systems that were more of a "vault" of personal health information[46] to disease-specific applications[47,48] to the current generation of online PHR tools owned by large, integrated healthcare delivery networks, PHRs have been offered in wide variety of shapes and sizes.[18] Current PHR offerings are diverse in terms of the types of health information collected, the way information is entered, the ability to import and integrate clinical information, and privacy and security attributes.[49] Though the Markle Foundation has outlined a list of distinct attributes of their "ideal" PHR, they also conceded that very few, if any, modern-day PHRs conform to this idealized definition.[18]

PHR architectures and models

Personal health records have been offered in many different forms; a 2009 inventory of PHR products and services found that almost two-thirds (60%) were web-based services, while other media included removable drives (USB drives, CDs), paper, medic-alert bands.[49] However, current thinking has shifted towards the PHR as a web-based or online system; in fact, the Markle Foundation later refined their definition of PHRs to be "an *Internet-based* set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it."[18]

There are a multitude of PHR models available, and most fall into the following three categories: standalone, integrated, and tethered.[15,33,50] *Standalone* models, also called *freestanding* or *third-party* PHRs, represent the simplest form of

PHRs, as they do not connect with any other system and require the patient to manually input data and update the record. At the other end of the spectrum are *integrated* or *interoperable* PHRs, which are interconnected with other systems. With an integrated PHR, data can be populated from a variety of sources, including provider-based records and EMRs, and often have many additional features and functions that allow communication between patients and providers. Lastly, *tethered* models fall somewhere in the middle, as they are institution-specific, web-based PHRs, sometimes referred to as "patient portals". They can be *provider-tethered*, which are internally connected to a healthcare provider's EMR, or *payer-tethered*, which are connected to the administrative databases of healthcare insurance companies. They allow patient access to parts of the EMR or database, but are essentially a "patient-facing extension of the clinician controlled [EMR], accessed via the Internet."[15] However, there can be overlap in these terms.[49]

PHR functionality

Within these PHR models, there is also considerable diversity in terms of the functionalities offered. At a minimum, PHRs provide basic tools that help people collect, organize, and store their health information.[51] This can include documenting medical history, emergency contacts, medication and allergy lists, immunization records, and other personal health information. More advanced PHRs offer additional features: scheduling appointments, requesting prescription renewals, patient education resources, secure patient-physician email, drug interaction checking, retrieving lab and other tests, and decision support tools.[46,50,52,53]

Current PHR development

PHR systems and features continue to evolve and the PHR field itself is rapidly expanding. There has been considerable development in the past few years, both in the private and public sphere. Private companies have put significant resources into their own Internet-based PHRs, such as Google Health, Microsoft

HealthVault, TelusHealth and many others.[15,54,55] Healthcare institutions have likewise developed and now offer patient portals (e.g. Toronto's Sunnybrook Hospital MyChart).[11,53,56-60] At the time of a 2008 report by the Centre for Information Technology Leadership, there were between 100-200 PHR products available in the US, and the numbers have likely since increased.[33,60] Healthcare institutions have also developed and now offer their own patient portals or PHRs, some of which have been developed through partnerships with private companies, such as McGill University Health Centre and MedForYou's Unani PHR.[11,53,56-59]

Despite the growth in the PHR market, Canada lags behind other countries, especially the US, in terms of PHR development. An inventory and analysis of PHRs conducted in 2009 revealed that the majority of PHR products/services are based in the US.[49] While there are some examples emerging from the Canadian landscape, such as the government-driven Alberta Netcare, Sunnybrook Health Sciences Centre's MyChart, or the subscription-based Mydoctor.ca offered by the Canadian Medical Association, PHR offerings are scarce in comparison.[61] In fact, it was only in November 2010, that Telus announced the launch of Telus Health Space (powered by Microsoft HealthVault) as one of the "first" consumer PHR platforms offered in Canada.[62]

Towards an integrated PHR

Regardless, the PHR continues to generate interest. The idea of an integrated PHR, in particular, has received considerable attention given its potential to link with the EMR. In fact, some argue that it is the PHR and the EMR *together* that will provide the basis for the transformation towards patient-centered care.[3,10,15,50] Tang and Lansky reason that "the mere installation of electronic health records (EHRs), even with more comprehensive interoperability, will not sufficiently engage patients in the health system" and that PHRs provide the "missing link" to bridge the patient-provider health information gap. Furthermore, the American College of Medical Informatics concluded that "PHRs integrated with electronic health records (EHRs) were likely to provide greater benefits than stand alone

records."[63] However, this particular PHR paradigm hinges on the widespread adoption of interoperable EMR systems throughout the country.[11] Federal and provincial policymakers in partnership with Canada Health Infoway have established the implementation of a nationwide interoperable EMR as a top priority.[2,64] In spite of this, Canada is still considerably behind in EMR implementation, ranking last in a study of ten industrialized countries on EMR adoption among general practitioners.[65] Clearly, there is still much progress to be made before the integrated PHR-EMR can become a reality.

Consumer interest in PHRs

Furthermore, consumer surveys seem to indicate that there is growing public interest in using this online tool; a 2008 survey of American adults found that almost half (46.5%) were interested in using an online PHR service.[66,67] Furthermore, there appears to be a perception of value, with almost 80% believing that an online PHR would provide major benefits to individuals managing their own health and healthcare.[67] A 2006 survey of 1003 Americans nationwide found that two-thirds were interested in accessing their own personal health information electronically, and the majority (90%) thought it would be personally important to track their symptoms or changes in health online.[68] The same survey found that many saw online records as a way to increase healthcare efficiency by reducing unnecessary repeated tests and procedures, which could lead to a reduction of healthcare costs, and believed access was likely to increase their quality of care.[68]

PHR Adoption

Despite all of the development and apparent consumer interest, adoption and use of PHRs among providers, patients and payers is low.[33] It was estimated that 70 million people in the US had access to some form of a PHR, mostly through their health insurer, and it was expected that an additional 200 million people belonging to America's Health Insurance Plans (AHIP) would be offered a PHR by the end of 2008.[33] In addition, there are now third-party PHRs available to anyone with Internet access (e.g. Google Health). In spite of high access, adoption

rates remain low. In fact, research has shown low adoption rates even when PHRs have been offered to patients for free.[23,69-72] A recent study (2009) conducted a web-based survey of 62 private commercial payers in the US; results confirmed that while implementation of electronic PHRs was relatively high among respondents, actual utilization of the systems was disappointingly low, with over half reporting utilization rates below 10%.[73] It is clear that significant barriers to widespread adoption of PHRs remain, although initial studies have only begun to investigate what these might be.

Barriers and facilitators to PHR adoption

Possible barriers and facilitators to PHR adoption have been discussed in the literature;[38,50] some relate to the healthcare system and culture, while others are at the technological, infrastructure and policy level.[4,15,50,74] At the present time, it is unclear what *exactly* is causing these low adoption rates, whether it is due to causes at organizational, technological or policy level, or other reasons. It may in fact be attributable to a lack of perceived value or fit between the technology and the end-user. After all, since the PHR is meant to be a consumer-centric tool, it is essential to consider what issues influence adoption at the individual-user level.

Individual-level issues affecting PHR adoption

A comprehensive review of the literature was therefore conducted in order to describe what is currently known about issues relating to PHR adoption at the individual-user level. Electronic databases (MEDLINE, EMBASE, CINAHL) were searched to find published literature. Snowballing (citation tracking) and hand searching of relevant journals was also used to identify relevant papers (Appendix 1 contains details of the search strategy). Within the published research, there was considerable heterogeneity, not only in the methodological approach (qualitative, quantitative, mixed methods) but also the characteristics of the PHRs offered (features, architectures, interfaces), participants, and contexts. Over half (55%) of the 29 retained studies reported quantitative data, whereas one-fifth (21%) were strictly qualitative, and the remaining studies reported a mix

of both, and included surveys, usage tracking, focus groups and individual interviews. The majority of studies were based in the US, which was not altogether unsurprising, given the relative abundance of PHR products available there; the remaining studies were based in Canada, UK and Europe. [34,75,76] PHRs were examined in a diverse array of healthcare contexts: primary care settings,[41,60,75,77-83] specialty clinics,[34,84-87] and hospital-based studies.[63,88,89] The remaining studies looked at PHRs in a community-based setting.[37,38,40,76,90-95] Some evaluated actual PHR systems or prototypes, such as patient portals to institutional EMRs, while others assessed views and opinions on hypothetical or proposed PHR services. Individual-level issues influencing adoption were identified in the literature, and included: (1) views and expectations of PHRs; (2) desired PHR characteristics and functionality; (3) security and privacy concerns; and (4) user characteristics (e.g. health status, computer and health literacy, race, age).

Views and expectations of PHRs

The value of the personal health record as perceived by potential or actual users has been explored in the literature. Quantitative studies have measured concepts such as "usefulness" and "satisfaction"[63] or have assessed expected or experienced benefits from using the PHR with questionnaires. Patients felt that using the PHR could help prepare them for visits with their physician,[41] improve their awareness and understanding of their health,[40,88] and improve their communication with their physician.[88] A grounded theory study[34] found that patients with inflammatory bowel disease perceived online electronic medical records to be of value to them in promoting a sense of illness ownership, patient-driven communication, personalized support and mutual trust between the patient and physician. In a community-based setting, Weitzman[94] found that there was high perceived value of features that allowed users to view, update and share health information with providers. Participants also expressed high value and interest in increased autonomy and control of their health information, though they also worried about bearing the responsibility for ensuring the accuracy and

integrity of the information. In the study by Earnest et al, both control and intervention groups in a trial of a patient-accessible medical record for congestive heart failure patients[84] anticipated similar benefits of PHRs: learning about their condition, coordinating care, memory, increasing participation in care, improving convenience/efficiency, and confirming accuracy of medical information. A qualitative study[75] found that patients believed that accessing online patient records could improve doctor–patient relationship, accuracy, promotes easier access to information, and improve shared management by facilitating self-monitoring of long-term conditions. In interviews with diabetic patients offered access to a diabetes-specific PHR, participants placed value on feeling that non-acute concerns were uniquely valued, there was an enhanced sense of security about health and healthcare, feeling more able to manage their health, and valuing feedback.[80] Interestingly, research suggests that some users may have high expectations for PHRs, which may not be fulfilled in reality: a study by Bryce et al[78] found a general trend whereby participants "anticipated features to be more useful than [PHR] users actually found them to be."

Desirable PHR characteristics and functionality

In addition to the perceived value of the PHR as a whole, certain features or functions of PHRs have been consistently identified as being desirable to users. Access to their medical record, especially lab or test results, was most frequently used or highly valued.[60,63,78,79,88,91]The ability to communicate with healthcare providers via secure email/messaging system through the PHR was also seen as a useful feature of the PHR.[60,78,79] Functions related to medication use, including online refills, were also considered important,[63,76,79] as were appointment scheduling and reminders systems.[76,77,91] Desirable characteristics also included cost (or lack thereof), and a few studies examined how users felt about paying for PHR services. One study[77] suggested that patients, across all ages, would be willing to pay a small annual fee for online services with their primary care physician's office. Participants were most willing to pay to be able to securely email with their physician (67%), online refills (62%), view their medical record

(60%) request appointments (57%) and make billing inquiries (52%). However, as the participants were sampled from the author's own practice, social desirability bias may have been a factor. Conversely, another study[78] found that most diabetic patients were opposed to paying for access, despite finding the portal useful. Vishwanath[92] found that subtleties in the way that PHRs were presented to users, or "framing," could affect willingness to pay for services, but this depended on whether the consumer was considered an early or late adopter of innovation, as outlined by Rogers' Diffusion of Innovation Theory.[96]

Interpretation of medical information was also an issue that arose in multiple studies; namely, the user's ability to understand and use the information presented to them in their PHR. Frequently, users complained about or sought out additional explanation for medical jargon and terminology, and desired greater clarity and simplicity in the presentation of medical information to avoid information overload.[37,83,84] Usability has also been widely considered as a crucial element in technology acceptance: "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."[97] As demonstrated by the study by Burke,[89] difficulties in navigation and page organization affected the overall satisfaction with the system, especially in novice users. A high level of usability and user friendliness was expected of the PHR.[95] Special attention to ease of use needs to be considered in specific populations of users, such as the elderly or disabled, that already experience difficulties with computers.[38] Clearly, usability is a critical element, and it has been argued that "adoption and effectiveness of PHRs will depend as much on systems and user interfaces as on the data in the records."[97] However, today's PHR systems are still in their infancy. Until PHRs have matured more fully, it is hard to assess whether adoption issues are a result of other factors or simply from frustration with inadequate systems.

Security and privacy concerns

Concerns with privacy and security have repeatedly identified as a major barrier to adoption in the empirical evidence. In one consumer survey, over half of respondents indicated they were not interested in using a PHR, 57% of those cited privacy and confidentiality as the reason for their reluctance.[98] Another survey revealed that 91% of people were "very concerned" about the privacy and security of their health information,[18] and other research support this notion.[10,94,99,100] Concerns about security and privacy were reported across many studies, both qualitative and quantitative.[37,75,76,83,84,93-95,101] Commercial use and exploitation of health data was a concern, as revealed in focus groups with patients from a primary care practice;[75] security concerns lessened after using the PHR but still remained. Similar results have been reported in other studies.[94] These concerns may be in part a function of who is sponsoring the PHR: a study of an employer-sponsored PHR found that issues with information security, lack of trust and concern with employer access to personal health information dominated.[95] There were certain populations where privacy appeared to be less of a concern. A focus group study found that disabled individuals felt that some of the privacy issues could be overridden in the event that emergency access to the PHR was required.[101] Walker[93] found that privacy was of greater concern to those who were healthy, as compared those who had chronic illnesses. Regardless of minor differences, it is apparent that assuring users of a secure, confidential environment for health information exchange within the PHR represents an important barrier to overcome.

Health status and adoption

Another important factor to consider in the PHR adoption is the characteristics and contexts of the end user. The effect of health status of the user on PHR uptake has shown conflicting results in the literature. Some have argued that the chronic disease population may be the first to adopt and benefit the most from PHRs, as they have a greater interest and motivation for tracking and managing their health.[34,36,52,102,103] In fact, several studies focused on disease-specific PHRs; for

example, in patients with diabetes,[78,79] congestive heart failure,[84] HIV/AIDS[85] and inflammatory bowel disease.[34] However, a case-control study by Weingart et al[60] used medical record review to compare the characteristics of 100 enrollees of the portal PatientSite versus 100 controls, and found that enrollees were in fact healthier and had fewer medical problems than non-enrollees. Another study found that amongst the patients at an HIV/AIDS clinic, users that registered for the PHR in the initial rollout tended to have better control of their HIV infection, as compared to the entire clinic.[85] However, both studies were preliminary or pilot studies and were limited by sample size, so it is too early to draw conclusions. In contrast, a 2004 study found that "heavy users of [their PHR] SSPARO had, on average, more clinic visits and were more symptomatic than less frequent users suggested that SSPARO was not simply a novelty for the worried well, but instead was used by those with the most potential to benefit from it."[84]

Moreover, health status of the user may influence what is desired of the PHR. A 2009 study[93] conducted focus groups with different groups, including healthy individuals and those with chronic illness. They found that healthy participants valued privacy far more than those that were sick. Lafky & Horan[101] investigated how health status affected user needs for PHRs by conducting 28 in-depth semi-structured interviews and a survey (n=210) with groups of "well," "unwell" and "disabled." They found differences between groups: the disabled group expressed a strong preference for a portable PHR, put a greater priority on using PHRs in emergency situation, were more active in using the Internet and computers to perform medical-related task, but also reported less confidence in the Internet than the non-disabled.

Not only is the health status of the user a potential barrier or facilitator, but the health status of other people in their lives may play a role. Caregivers of the chronically or severely ill have been identified as potential end-users of PHRs. One study[89] examined the utilization patterns of a web-based patient-accessible electronic health record in parents of children undergoing congenital cardiac

surgery at a Miami hospital (n=270). They observed a very high adoption rate, with 93% becoming users and with an average of 25 logins per family. However, given the severity of the childrens' conditions, the observed adoption rate may not be generalizable to all caregivers.

The digital divide and adoption

Other characteristics of users may represent barriers to adoption. In particular, computer and health literacy may represent a larger barrier to use, especially in older adults, minority and low-income populations.[38,74,104,105] This has been discussed as the "digital divide" between those with and those without the ability to access and effectively use information technology; research suggests that it may largely be a function of race/ethnicity, education, and socioeconomic status.[15,60,81,106,107] Kim et al studied the usage of their system, PHIMS, by elderly and disabled patients in a community setting[40,90] and argued that a community-based resource sharing and support strategy could help overcome some aspects of the digital divide. They set up a computer room with PHR in a low-income housing facility serving elderly and disabled populations, with support offered by nursing students. However, half of their 46 participants (average age of 66) only accessed the system on one occasion, and a related study by Lober identified patient-level barriers including computer literacy, computer anxiety, health literacy and physical impairment.[38]

Evidence also suggests that race or ethnicity could play a role in the adoption or acceptance of personal health records. A study at an HIV/AIDS clinic found that enrollees of the myHERO PHR were more often Caucasian and less often Hispanic.[85] Similarly, users of a medication module offered through an integrated delivery network patient portal were more likely to be Caucasian and less impoverished than non-users.[41] A cohort study[81] found racial disparities in use of a PHR in a managed care organization that could not be accounted for by differences in education, income or Internet access; enrollees were more likely to be Caucasian (42% versus 30% African American). Likewise, the case-control

study of PatientSite found enrollees were more likely Caucasian.[60] Ross[86] found that Black Caribbean individuals had significantly less access to the Internet and less acceptance of electronic data collection. Again, these racial disparities in adoption may be related to other factors, such as Internet access, education, income, health and computer literacy. "Patients with lower incomes and lower levels of literacy, especially people of color, bear a disproportionate burden of disease, but are less likely to have experience with or access to the Internet. In addition, people of color and those with lower income and literacy levels are less likely to have access to healthcare, a regular physician, and overall receive lower quality healthcare when they do have health insurance."[18] This is a matter that needs to be addressed, as it suggests that those in poorest health and lowest access to regular care may be the least likely to have access to a PHR, even though they may be most likely to benefit from it.

Age and adoption

The effect of other user characteristics, such as age, on adoption is even less clear. On one hand, younger adults use the Internet with greater frequency[45] but older adults generally have more health issues and therefore may be more motivated to use a PHR to manage their health. However, as suggested by the Markle Foundation Report, "the public is unfamiliar with and uncertain about electronic health records, and older people are more hesitant than younger to use such a system,"[18] and this notion seems to be supported by consumer surveys. In the published literature, several studies found that the average age of PHRs users was over 50,[37,39,75,84] though this may be related to the specific population that were studied (chronic disease patients, veterans). Conversely, other studies have reported that PHR users were actually younger than the average population. [60,85,87]

The age of the user may also influence attitudes towards PHRs. Weitzman found that younger users had a more limited understanding of consequences of privacy breaches, and individual control over health information was more valued by younger participants.[94] Through individual and group interviews, they also found

that younger individuals and students (approximately 18-35 years old) appeared to be more familiar with the concept of subscribing to a data system, though had not considered this in the context of health information.[94] In the series of focus groups conducted by Walker[93] "young consumers" 18–25 years old (college students) were the only ones that did not currently keep health records, as compared to other participants with chronic illnesses, caregivers, or older adults. Though younger users may be less conscientious about keeping health records, they are also more apt to be computer savvy. Weitzman found that younger users appeared to be more sophisticated than older users about technological strategies to ensure privacy (e.g. encryption, digital signatures, etc), but also did not seem to consider the potential consequences of information sharing.[94] Focus group participants, who were 18-35 years old, had a "naïve appreciation for potential risks to insurability or employability related to disclosure of health information." Interestingly enough, in the same study older participants felt that they had "less to lose" than younger participants with respect to a breach in privacy; moreover, concerns about stigma or discrimination from the release of personal health information were expressed.

Though this seems to suggest that there are differences in PHR attitudes with respect to age, only a few studies looked specifically at younger populations. One qualitative study[83] looked at teens 16–18 years old (n=28) and their attitudes towards a patient portal. Teens demonstrated an enthusiasm for the portal and the ability to access their primary care physician, seek reliable health information and make appointments, but had concerns about confidentiality, especially with regards to what might be shared with parents. Ross et al[86] compared specialty clinic patients to a community sample, both between 16–25 years old, to assess the preferences of the use of ICT in sexual healthcare, and found that 60% considered electronic collection of sexual history "acceptable". However, the authors admitted there might have been issues of oversampling and differences in response rate.

Summary of Literature Review

Development and research in PHR is still in its early stages, and the market is evolving quickly. Despite excitement from stakeholders, consumer interest, and available options, adoption rates have been low. While barriers and facilitators to PHR adoption have begun to be explored, no conclusive evidence adequately explains the low uptake. Possible individual-level issues have begun to be examined, including the views and expectations of PHRs, desirable characteristics, security and privacy concerns, and possible effects of health status, the digital divide and age on adoption. In addition, there has been considerable discussion about barriers to adoption in editorials, commentaries, reviews and position papers.[4,20,23,50,74] However, only 29 primary studies were identified that considered individual-level issues from the perspective of the end-user, and most did not even examine them as the primary objective. Very few studies provided an in-depth look at these questions, and as a result, there is a lack of conclusive evidence regarding these issues.

PHRs are still an immature technology. This is reflected in the literature, which largely consists of pilot or preliminary studies with emerging PHRs. The considerable heterogeneity in PHR models, features, contexts and populations studied also make it difficult to draw generalizations. The most consistent evidence centered around the PHR itself: namely, features or characteristics of the system and concerns with the system. Desired PHR characteristics from the patient perspective included access to medical records, secure messaging, appointment scheduling and medication refills. A PHR that was simple to use and easy to understand (especially with respect to medical information) was also very important. Concerns with using the PHR included breaches of confidentiality and security, and the misuse or exploitation of private health data. Though some findings suggest that younger, healthier users are more likely to use PHRs, no studies looked specifically at the healthy young adult population, nor did they consider the potential of PHRs in preventative health. Research has mostly focused on older and chronic disease populations and management of disease.

This review demonstrates that there are still many gaps in our knowledge with regards to PHR adoption and certain populations and potential applications have not yet been adequately considered. Personalized health interventions like the PHR are unlikely to have a "one size fits all" solution. Consequently, more in-depth research is needed to identify how PHRs may be used, and equally where and why they will work and for whom.[23,37] This thesis is a first step in addressing and identifying the issues affecting PHR adoption in young healthy adults by describing the views of this population and their expectations of using a PHR.

METHODOLOGY

Research Design

Given that little is known about the views and issues influencing adoption of online personal health records, especially in the young adult population in Canada, a qualitative descriptive design was chosen for the present investigation. The aim of qualitative description is a "rich, straight description of an experience of an event"[108] in a language similar to that of the participants. This approach is cohesive with the objective of the study, which has a mostly descriptive purpose, as well as the nature of the research questions, which are concerned with what the views of young adults are and what they expect from using it. Specifically, *basic* or *fundamental* qualitative description as described by Sandelowski (2000) was employed with the aim of gaining firsthand knowledge of participants' views and experiences with a particular topic, namely PHRs.[108,109] It is also particularly well-suited to questions such as "What reasons do people have for using and not using a service or procedure?"[110]

Setting and Participants

This study was conducted over an 8-month period (from September 2010 to April 2011) in a community setting in Montreal, Canada. The target population for this study was young healthy adults living in Montreal. The aim was to capture PHR views and expectations of the "typical" young adult, who generally has no major health issues and does not have extensive interactions with the healthcare system. Individuals who have serious or multiple health conditions represent a very different perspective (the "patient"), and their health issues and experience within the healthcare system could produce very different needs and expectations from a PHR. Given the complexity of these issues and the limitations on time and scope of this study, it was decided to focus on the "typical" healthy young adult and therefore exclude participants with major health conditions. Individuals who were between the ages of 18 and 34 years old were considered eligible for the study. There were no exclusions with regards to gender, ethnicity, or computer/Internet experience. No prior knowledge of PHRs was required to participate. However, as

focus groups were conducted and analyzed in English, eligibility was limited to people able to speak English though it need not be their primary spoken language.

A purposeful, flexible sampling strategy was employed in attempt to select participants "who are likely to generate appropriate and useful data."[111] As previously mentioned, keeping in line with the qualitative descriptive study design as outlined by Sandelowski, maximum variation sampling was used, wherein a wide range of cases are selected to obtain variation on the concepts of interest[112] – so within the targeted population, a mix of male and female participants of varying ages and backgrounds was sought out. Though purposeful, there was also an element of 'convenience' sampling, to the extent that subjects were included on the basis of their accessibility and willingness to participate. However, Green (2009) argues that "convenience samples, based on networks of contacts, may be sufficient for exploratory or pilot studies."[111]

Initial recruitment strategies focused on undergraduate and graduate students at English-language universities in Montreal. It was reasoned that students would be a good initial population to target, as they would likely be more open to adopting new technologies such as PHRs, given that they are relatively well-educated and have a high degree of computer literacy. Based on early analysis of the first two groups, later recruitment broadened the scope to non-students to capture their views and expectations.

Recruitment strategies included:

1) Placing recruitment posters on university campuses (McGill & Concordia University) and within the community;
2) Advertising in online classified systems (McGill Classified, Concordia's Con-Ads, Montreal Craigslist);
3) Direct recruitment at student events (McGill Activities Night); and
4) Recruitment through personal networks.

Interested participants were directed to contact the research coordinator (the

author) by phone or email (indicated on ads), who then provided more detailed information about the study. Participants who met the eligibility requirements (i.e. between 18 and 34 years old and with no major health conditions) were the focus group, so long as they met the criteria. To accommodate different schedules, focus groups were planned for weekday evenings in a conference room at the Department of Family Medicine at McGill University. A draw for a $50 gift certificate was offered as an incentive for participating, and food and refreshments were provided during the focus groups. A total of 29 participants were involved in the present study.

Data Collection

The primary method for collecting data was focus groups. Focus groups seek a broad range of ideas on an open-ended topic and are well suited to exploring users' views of a service or product.[113,114] As Krueger and Casey (2000) detail, "it is a way to better understand how people feel or think about an issue, product or service." Groups are small discussions typically composed of five to ten people but can range from as few as four to as many as twelve.[114] Focus groups have the "potential for producing considerable information in a fairly short space of time," as well as a greater breadth of ideas. Focus groups are widely used in health research, and their market research tradition is appropriate in exploring a "consumer" health product or new initiative such as the PHR.[111] Participants are selected because they share certain characteristics – in this case, all relatively healthy individuals from the same age group living in Montreal.

Before beginning the group discussion, informed consent forms were distributed to participants and included a brief explanation of the study and its objectives in lay language, as well as described the rights of the participants and provided contact information of the study investigator in the event of any questions. Participants were also given pre-interview questionnaires, comprised of 26 questions pertaining to sociodemographic information, computer/Internet use, health and prior PHR knowledge and attitudes. Data from questionnaires was used

to characterize and describe who the participants were, in order to help situate the research and its findings. Questionnaire data complements and supports interview data, and this additional source of information was considered suitable for a qualitative descriptive design since the aim was to provide a rich detailed description.

Once consent forms were signed and questionnaires were completed, a brief five-minute presentation was given by the author as the facilitator to introduce the topic of personal health records to the group. This included the definition of a PHR, as well as different types and features available. The group discussion followed the presentation and lasted 60-90 minutes in length and was guided by the author as the facilitator. Since analysis would focus on the semantic level, group dynamics were not considered directly in the analysis. An interview guide with a set of seven open-ended questions was followed, though successive questions and specific probes evolved slightly as part of the research process. Focus groups were recorded and subsequently transcribed by the author. Though time-consuming, transcription is considered worthwhile as an initial step to become familiar with the data, and has been argued to be a "key phase of data analysis within interpretative qualitative methodology."[115] A total of four focus groups were planned with an expected 20-32 participants (i.e. about 6-8 participants per group).

Data Analysis

Transcripts of interview data were analyzed using inductive thematic analysis and focused on the semantic level. Thematic analysis is a method for identifying, analyzing and reporting patterns (themes) within data.[116] Frequently, it can go even further and interpret various aspects of the research topic[117] and try to theorize the significance of patterns and their broader meanings and implications.[116,118] With an inductive thematic approach, themes identified are more closely linked to the data,[118] which is preferable given the exploratory nature of this study. "Inductive analysis is therefore a process of coding the data without

trying to fit it into a pre-existing coding frame, or the researcher's analytic preconceptions. In this sense, this form of thematic analysis is data-driven."[116]

Thematic analysis can be used across different qualitative approaches, and is one of the methods typically used in qualitative description, aside from content analysis.[110] Thematic analysis was considered preferable to content analysis, the latter of which provides counts and has smaller units of analysis of words and phrases as opposed to ideas or concepts.[116] Moreover, it is useful "for answering questions about the salient issues for particular groups of respondents or identifying typical responses."[111]

The six different phases of thematic analysis, as proposed by Braun & Clarke (2006), were followed: (1) transcription, reading and re-reading of the transcripts allowed for initial familiarization with the data and for preliminary ideas to be noted; (2) initial codes were generated systematically, and represented features of interest within the data; they are the "most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon;"[117] (3) codes were subsequently collated into potential themes, and (4) then were checked against coded extracts and the entire data set, generating a thematic map of the analysis; (5) an ongoing analysis worked to name themes, refine the specifics of each theme, and determine what aspects of the data each theme was capturing; and finally (6) these themes were examined in the light of existing knowledge. NVivo8 software[119] was used to assist in coding and organizing the data, and SAS 9.2 statistical software was used to obtain basic descriptive statistics from the questionnaire data.

Ethical Considerations

Ethical approval was obtained from the McGill Institutional Review Board (IRB), including consent forms and questionnaires for participants, as well as recruitment ads. Anonymity and confidentiality of individuals participating in the project was assured by identifying participants only by a code in transcripts. Participation in

the study was completely voluntary and participants retained the right to withdraw at any time. All information obtained was used for academic purposes only. Only the author and her supervisor have access to the primary data, which is kept at the McGill Department of Family Medicine. Communication of results will include presentations and papers, and any publication of results will not identify any individuals.

RESULTS

Four focus groups were conducted with a total of 29 participants, with group discussions lasting on average 90 minutes. The smallest group had four participants, while the largest had ten. Table 1 presents the characteristics of focus group participants. The average participant was between the ages of 25-30 years old with at least an undergraduate degree, and was an English-speaking Caucasian who regularly used the Internet.

Table 1: Characteristics of focus group participants (n=29).

Participant Characteristics	n (%)
Age range in years	
18-20	2 (6.9)
21-24	4 (13.8)
25-30	17 (58.6)
30-34	6 (20.7)
Male	14 (48.3)
Highest level of schooling	
High school	5 (17.2)
College	2 (6.9)
Undergraduate degree	15 (51.7)
Master's degree	7 (24.1)
Health/medical sciences background	8 (27.6)
Permanent resident of Quebec	23 (79.3)
Caucasian	20 (69.0)
English as primary spoken language *	22 (75.9)

*missing response=1

Participants were also asked about Internet use, health and prior PHR and Internet privacy attitudes in pre-interview questionnaires (see Appendix 4 for additional details). When asked how frequently they used the Internet per month, the majority of participants (89.7%) used it at least once a day. In fact, over two-thirds (68.9%) used the Internet from home at least 10 hours per week, and one-fifth (20.7%) used it 30 hours or more per week. Participants used the Internet for a wide variety of purposes, most frequently for email (100%), general browsing (100%), Internet banking (96.6%), reading the news (89.7%), online shopping

(82.8%) and downloading music (82.8%). About three-quarters (75.9%) reported using the Internet to search for medical or health related information in the past 12 months. Of the 22 people who *had* searched for medical or health related information, lifestyle information was most frequently sought after (100%), which was described as diet, nutrition, exercise, health promotion, and illness prevention in the questionnaire. Disease-specific (63.6%) and symptom-specific (59.1%) information were also frequently searched for on the Internet.

When it came to how participants perceived their own health, about two-thirds (65.5%) rated it as either "very good" or "excellent", about a quarter (27.6%) rated it as "good", and one participant rated their health as "fair". No participant perceived their health to be "poor". In terms of access to regular primary care services, about one-third (31%) had a regular physician in Montreal, one-third (31%) had a regular physician outside of Montreal, and the remaining third (34.5%) had no regular physician. Five participants reported having a chronic condition but still rated their health as "good" (2/5) if not "very good" (2/5) or "excellent" (1/5). When it came to their attitudes towards PHRs, over half (51.7%) though it would be "very useful" or "extremely useful" in helping them manage their health. About a third (31%) thought that it would be "somewhat useful" and one-tenth (10.3%) were not sure. In terms of participants' concerns about privacy about on the Internet, there was a range of responses, though about one third expressed a middling level of "somewhat concerned" (31%). Almost two-fifths (37.9%) were "very concerned" or "extremely concerned" about privacy, while a couple (6.9%) were "not at all concerned". However, when it came to concerns about privacy or security of putting their health information on the Internet, responses were more polarized, with almost half of participants (48.3%) being "very concerned" or "extremely concerned", about a third (34.5%) "a little" or "not at all concerned" and the remaining (10.3%) respondents being "somewhat concerned."

PART 1: VIEWS ABOUT ONLINE PERSONAL HEALTH RECORDS

With respect to how young healthy adults viewed online personal health records, a few broad themes were elaborated: (A) perceived advantages of a PHR; (B) who they envisioned as potential PHR users; and (C) concerns about PHRs.

Theme 1A: Perceived Advantages of a Personal Health Record

A comprehensive, consolidated record

Most participants saw a main advantage of the PHR as being its potential to bring together disparate parts of their health record and health information. Participants stressed the value of having their information *all in one place*:

> "I had a family doctor when I was a kid, but as I grew older, we moved and we never got a family doctor again. And so all of my health records are all around, scattered around. And now I'm in Montreal, and like, I've seen a couple of different doctors, and none of my health records are together. So having that all together for any doctor that I go see would be really useful because that means that they have that much more background knowledge on me, and being able to tailor my medical treatments to me, would be better."

They believed their personal health record should include lists of current and past medications, vaccinations as well as their medical history, appointments, diagnoses, treatments and lab results. Having a comprehensive and "more consolidated record" was thought to enable a *more complete picture of one's health*, for both participants and their healthcare providers, which could in turn lead to better care and safety; with a fragmented record, "doctors [could] miss a big piece of the picture." For example, several participants regarded a consolidated record of one's medications as a way to improve safety by identifying potential contraindications or conflicts:

> "I'm not on any consistent medication yet, but what if in the not too distant future I am? I like the idea of this system – a system – potentially telling me about conflicts, you know?"

Accurate record of medical information

Moreover, participants acknowledge the fallibility of their own memory, and viewed the PHR as being a record or *reference they could refer back to*:

"Sometimes you forget. You don't remember when you last saw that doctor. So I think that just for your own reminding, you know, just the fact that they're your own files, they're there for you." Having a more *accurate record* of medical history and information and being able to relay those details to their physician was also seen as a means to improve care:

> "In terms of actually going to the doctor and being able to have all of my information in one place, clearly, so we can look at it together, and we can say okay – instead of me guessing and saying 'oh, the last time I was on antibiotics was, I don't know', you know?"

Given the importance of accuracy, participants also wanted to be able to verify the information in their electronic medical record: "So you could, even yourself, double check your own record. If [the PHR is] tethered, you could have access to your file, you could say "I never took that medication," or "you know, you're missing important allergies that I have."

Accessibility of health information

Another significant benefit was the *accessibility* of health information. Participants believed that having an online system like the PHR should allow them, as well as healthcare providers, access to their health information, anytime and anywhere.

> "Just having the opportunity of carrying all of your information, and for different doctors to be able to access that information, no matter where in the world you are, that's kind of the most important part, for me personally."

Many considered this particularly useful for travelling:

> "I'd like it for travel - I travel a lot, so if I could just get the information. So when I go to the doctor there, [instead of spending] half an hour explaining my history, he could just look at it, right away."

Participants also saw the benefit of having access to the information if they moved or lived abroad: "What if you move, and when you want your information transferred, then you can have it, it's easier." As one participant elaborated:

> "Even when you switch doctors, they don't necessarily get all of your pre-dated information, which in my opinion is kind of ridiculous. I'm twenty six years old, I've been in Montreal for three years, it's like I haven't existed for the past 26 years. I have to speak to someone in Nova Scotia to

> get any kind of record, or health references. And here, I don't have one specific doctor. I've gone to a clinic once, twice. So it's like, as far as getting any kind of accurate information even from the people that I'm seeing now, it's like it doesn't - it really doesn't exist."

Moreover, for participants, accessibility implied not only access through a computer, but also through their smart phone: "We don't always have access to an actual computer. Most people have access to their iPhone, or stuff like that." [P05] As one participant reasoned: "Well, if you can do everything else on your phone, then I would think you could do that too." [P21] They also saw the potential for using the PHR in emergency situations, where healthcare workers might need access to their health information, such as allergies or medications:

> "I think a very practical application of the personal healthcare record could be kind of one of those Medic-Alert bracelets, you know? Say something were to happen, you were unconscious and not able to communicate allergies or whatever - you would have that card, and it would have all that information on it."

Integrated health record

For the majority participants, one major way they presumed an online personal health record to be of value lay in it being a complete, comprehensive, accurate and accessible source of their health information. However, they were not interested in having a PHR that acted as a standalone record or vault of their health information. "I don't think I would bother with it if it was standalone, to be honest." Participants believed a PHR was valuable so long as it was able to connect to other systems and people, namely as an *integrated PHR system*. As one participant insisted: "It wouldn't be anywhere near as valuable if it wasn't connected to my doctor."

Improving efficiency of healthcare system

Participants believed that another potential advantage of adopting of an integrated PHR system would be improving the efficiency of the healthcare system. For one, they thought that PHRs integrated with EMRs could help facilitate better communication and information access, between patients and physicians, but also between different providers: "One of the central benefits of it would be the

efficiency of having different doctors communicating with each other." This was seen as particularly true in Quebec, where many people did not necessarily have a regular family physician:

> "Given our context, of the Quebec system and the shortage of doctors, so many people don't have a family doctor, so they're never seeing the same person. They're always seeing somebody different. So being able to go to any doctor, any clinic, and they can pull up that information and see, I mean, that's priceless."

Many viewed the PHR as having the potential to improve efficiency of services through various mechanisms: screening or remote assessment, reducing unnecessary visits, prioritizing care, and eliminating duplicated efforts. Some participants proposed that the PHR could be to facilitate screening or assessment, whether through an automated system, or electronic messaging with the physician:

> "I think another advantage would be that you can … have all these symptoms and you're kind of concerned, but you're not really sure if you should go to the doctor or not. And you kind of 'click' and they would send it to the doctor, and the doctor would look at it and would be like 'no, you're fine, stay at home.' Or 'come into the office right now!'"

Even screening through an automated algorithm in the PHR might reduce unnecessary visits to the doctor:

> "I'm sure that this would cut costs, to the health system, *enormously*. Because instead of going to the doctor when they feel ill… people who have less serious conditions would have whatever program analyze what they've inputted into this PHR and say "oh, I just have a cold.'"

Being able to assess whether it was necessary to go in person to see the doctor would also be advantageous for the patient:

> "I'm interested in being able to have a dialogue with a physician, where you don't have to actually go there and wait for an appointment. Maybe you have a concern, like I've been having really horrible headaches for the last week, and you just ask for a general opinion, and then get some feedback, like 'you should definitely come in', 'maybe you could try a few things' … Without having to get on the phone, and wait to talk to people, and just being able to do things on your own time."

If patients were pre-screened, this could help providers *prioritize care* in terms of need: "You could also make it more efficient, because you can have it organized depending on how urgent the situation is." With an integrated system and

centralized health information, individuals could theoretically not need to spend the time repeating one's medical history each time they saw a new physician. Having access to more information was also believed to be able to provide more directed care, as one participant noted:

> "If [the doctor] can spend just ten minutes with [their] patient, and … my doctor knows exactly what's wrong, and I get out in ten knowing exactly what needs to be done. My doctor might be able to fit in five or six extra people that day. You understand, with the long waiting list we have?"

Research and identifying population trends

Participants also discussed other theoretical applications and benefits of the PHR. With information being "already collected" within a PHR, many participants proposed that this information could be aggregated anonymously and used to identify *population-level trends* and "for *research purposes* – you can see, some people have this lifestyle, and they're healthier." Collecting information online allowed the possibility for access to a large pool of data:

> "I think that the health of everyone being hosted in the cloud really helps in identifying trends, within groups. Just having an outside of the box perspective of how things are initiating. I've seen that Google has tracked the flu, like, so you see that the flu season is coming and you can see that you can basically track that."

Despite a desire to ensure privacy of their health information, they reasoned that "the information's there, so it would theoretically available for that purpose."

Theme 1B: Potential PHR Users

Age and computer literacy

Participants debated who might be most likely to use and benefit from a PHR, and brought up salient issues regarding challenges of access and use by specific populations. They questioned whether older adults might have difficulty or be reluctant to use a PHR, despite having more health issues to keep track of. A lack of familiarity with technology or computer literacy was deemed a significant barrier to adoption:

> "I could see older people having problem with the technology aspect of it. You mentioned older people tracking their medications and everything,

> but I don't really see - but then again, it's not like it's going to happen tomorrow, so maybe by the time it like, actually happens, the generations will have been around technology enough. But today? No. Well, there's a whole generation of old people that would be really confused."

Some believed that their generation (i.e. younger adults) would be more apt to adopt this type of technology than older adults, since they are more accustomed to using computers and the Internet in their day-to-day life:

> "People our age, we all use the Internet, and when we get older, I think we'll still be using the Internet. I think it would be a lot easier and more feasible for us to do that than to just expect older people now to start doing that. I don't think older people now would really do that at all. But I think us, in the future, would."

Health status and the "worried well"

Participants also brought up the idea that individuals with chronic health conditions might in fact benefit more from using a PHR regularly:

> "Any kind of condition where you need to monitor everyday or on a regular basis; for example, if you have cancer or something like that, you monitor your medications, you monitor your radiotherapy appointments and things like that, where you have too many things to think about."

Interestingly, though it was thought that people with more health issues might benefit more from PHR use, it was also acknowledged that *healthier individuals might be more likely to use it*:

> "This is maybe kind of cynical, but it's probably people who are a little healthier to begin with anyways that are interested in it? Because if you're really unhealthy, and really unsatisfied with your lifestyle, I think it might be great to do, because it could be a wake-up call, but it could also be really discouraging if you're in that situation. So it might only reach a certain crowd that doesn't need it as much."

The notion of the "worried well" was thought to be further complicated by disparities in education and health literacy. Some participants expressed concern that a lack of education and health literacy might limit access to a PHR:

> "I think one of the main things I can see here is you're expecting everybody to be really educated, and that's not the state… I think this is way too complicated, and then you will end up only targeting, maybe only someone with a university degree or something, who's very medical, who knows a lot about health, and who would anyways be very health conscious and would do that anyways."

Caregivers

Lastly, several participants saw PHRs as being useful for caregivers: "I actually imagined this system almost working more through caregivers… especially when you were mentioning the elderly before and how they wouldn't be likely to use this – but you know, their caregivers, or the people who are running the home, may monitor some of their symptoms."

Theme 1C: Concerns with Using a PHR

Misuse of information by employers and insurance companies

When it came to concerns about using a PHR, how personal information could be used or misused and by whom, was a dominant topic. Security and confidentiality were significant concerns. Many participants realized that a consequence of putting information online was that it became "fluid and accessible"– not only to its intended recipients, but also to other parties, such as hackers, private companies, or other unwanted individuals. As one participant put it:

> "Besides the fact that I don't trust the information, I don't trust the transfer of it. I don't like the idea of Google being able to see what's wrong with me. I don't like the idea of doctors and then nurses - it's a file on you, for people to access your stuff. If it was just one doctor, that I could give a password to, that would be different, but the medical system, as we all know, is very kind of, fluid."

Participants conveyed a reticence of putting sensitive information in the PHR, for fear of losing their confidentiality: "If I had a serious chronic health issue, I would be nervous about putting that information out into the cloud." In particular, many were concerned that the information could be accessed and used by employers or insurance companies:

> "This sounds very very paranoid, and the likelihood is probably incredibly small, but you know, it being used by employers, to screen applicants. That information is private, and personal. And you look at Facebook, and that's being used, you know? Employers are going on Facebook to check people's profiles before they do hiring, so - could it be used like that, another tool for screening out, you know, potential applicants. It's a little farfetched, but it's a possibility."

> "In the wrong hands, it could spike your insurance way up and so that's the biggest obstacle."

Another participant countered with the idea other types of information people already choose to share and put online is equally likely to be scrutinized:

> "If you're willing to put, like, 'Bikini Cuba Vacation' photos and 'Big Margarita' photos and stuff on your Facebook that can be just as detrimental to your work status, as putting your general physical health stuff. A lot of places that you work at also have healthcare benefits, and those packages reap the insurance stuff – with that stuff, prescriptions and anything else goes to them anyway. So they're already halfway there."

It was thought that the repercussions of personal health information getting out and being used to discriminate against you could be persistent, as voiced by one participant:

> "I could see the employers not wanting to hire someone based on their medical records. And you know, let's say this goes on a generation or two, and someone realizes 'oh, your parents have a hereditary medical condition'. So it's not even you they've diagnosed anymore, it's your parents, and oh, you have a 75% chance of having the same thing."

Ultimately, this apprehension might affect what information people chose to put into the PHR, as one participant noted:

> "When you apply for a policy and they…call your doctor and ask for your history. If you're actually tracking things, and you feel like that's going to go into that equation, you're not going to be completely honest."

Stigma and discrimination

These security and confidentiality concerns were magnified in cases where individuals might have a *stigmatizing* medical condition. Many participants questioned putting such private information into the PHR, envisioning scenarios where the information could get "out there" and they would lose control of it:

> "It would depend on the condition, if I had herpes, I would be less likely to fill it in, than if I had the flu - so something embarrassing – say you're having a flare-up, and you have herpes, and your wife doesn't. Would I fill this out and send it? I don't know if I would."

Thus participants felt it was important to maintain control over whether sensitive health information was shared, especially if one had a stigmatizing condition, even with their healthcare providers. They worried it would *change the way they would be treated*:

> "If someone is having a psychiatric disorder, or HIV, or anything that has

> stigma around it, and they don't want anybody to know about it, I think they should have the option to hide that… You don't want [the doctor] to treat you differently."

However, despite the points that were raised, they also conceded that these issues were not a current concern for them, personally, since they were still healthy:

> "Maybe if I would have any sickness, I don't know, let's say, for example, I have AIDS, maybe I would be a little bit hesitant to putting my [health information online] – because I'm healthy, I think that's why I don't mind going and using it."
>
> "Because I don't feel like I have anything to hide, I'm not super worried."

Use of information for advertising or profit

Access by private companies was seen as a probable way in which their health information could be misused. Participants realized the value of personal information and were aware that it could be traded as currency: "I think there's a huge market for that kind of information out there. I'm sure the traps are already there, and already designed it, they've already thought about all of that." They were not naïve to the idea that their information was already being collected and sold, especially for *advertising* and *marketing* purposes, and acknowledged that it was the underlying business model in many of the sites they frequented: "On Facebook, everything's being sold, under the table. You're signing these huge things and your information's out there. And Google may be the same." Though they accepted this as a possibility for PHRs, especially free PHRs, they still felt conflicted about it:

> "I don't think they should just sell their advertising space to anyone. I don't want to go put in my stuff and see advertisements for drugs and stuff. I think that, it would be really dangerous."
>
> "I think as long as it's not popping up in my face, if it were on the side… I wouldn't completely be pissed. But I think if it starting popping up all the time … well, [that] would get fairly annoying."

Breaches of security by hackers were also considered – "What if someone hacked in to the system, they could get everything, and use it against you"– but not considered as likely as information being used for advertising. A few participants proposed usernames as a way of ensuring anonymity: "If it's just a user name that

no one can attach to you, and you're really worried, and you don't attach it to anything, it's a user name you use for that exclusively, that would certainly get rid of some of the problem." Concerns with security and confidentiality were mitigated by *who was sponsoring the PHR*. Public or government institutions were considered to be more trustworthy in terms of holding personal health information, as they were thought to be "free of outside corporate influences": "Certainly I wouldn't trust a private institution to do it. The government I have a little more faith in."

Data integrity and complexity

With an online PHR, participants also expressed concern about ensuring the *integrity of the data*, and were worried that the information could be changed, lost or deleted: "Is there a backup system that's happening anywhere? What if the whole system just goes down?" Another participant likewise felt unease at the prospect: "Not only it getting stolen, but it just getting ruined somehow. Deleted. Because, there's something so disconcerting about the idea of a lot of information existing only digitally. And having no tangible record of it." Despite apparent misgivings and concerns about security and privacy, these issues did not appear insurmountable. Several participants cited Internet or online banking as an example of how security concerns could change:

> "I say [I'm worried but] I know full well that I bank on the Internet and I use it for a lot of other things. So I say, yeah, I'm worried about it, but would that stop me? Well, I don't know, that's another question."

Participants also considered the challenge of capturing the *complexity* and richness of health information within an electronic format, and finding a balance with ease of use:

> "Also there's the fact that not all health data can be really quantified or put into a neat little checkbox, there's a lot of judgment on the part of physicians to sort of see between the ambiguities… you're putting it in the hands of lay people to try and fit it in the format of the site, and then the electronic format, where everything has to be binary or neat little lines, there are some things that are subtle and can't really, that don't lend themselves well to that kind of format."

The health professional perspective

Many participants also considered potential issues from the perspective of the health professional. One participant questioned whether giving patients access to their medical record could *change the patient-physician dynamic*: "Now that it would be seen directly by the patient, right away, I think that it sort of puts doctors on guard more, I would think. It's no longer just the doctor's record for themself of what happened, it's actually becomes a different document, in a way." Another envisioned legal consequences:

> "You have this patient who's constantly on or using a PHR, and they're comparing with each other, and you know, maybe somewhere perhaps it may not be a huge thing, but would it increase the chances of suing the guys? Suing the professionals? Because you're holding them to the whole thing, you are comparing notes, maybe there was an error, maybe the person thinks… that the professional made an error in judgment or whatever. Having so much power, is it good?"

A few were concerned that the PHR could engender unrealistic expectations in potential users about how it would be used by physicians: "If I have all these personal health records or something like that, I mean, it's sort of – maybe I've misunderstood, but it sounds as though, you know, there's this idea that someone's looking at these." Participants were also worried that generating too much information was not necessarily a good thing, especially in tracking day-to-day details, and could be seen as a burden to their healthcare provider:

> There is potential to be a lot of information here… who's going to sort through this? Does the physician have time to look through all the pages and pages of data entry?"

Participants wondered whether doctors would actually use the PHR: "I'm also concerned as to whether doctors would actually use it, because I know a lot of doctors are already stressed, pressured for time, some are really set in their ways."

PART 2: EXPECTATIONS FROM USING AN ONLINE PHR

When it came to how they *themselves* envisioned using a PHR, different ideas emerged from what they had proposed as hypothetical benefits. Several key themes were identified: (A) what characteristics they felt were important or desired in an "ideal" PHR; (B) using the PHR for preventative health and lifestyle; (C) taking more control of their health; and (D) ensuring the investment of time and effort into the PHR was worthwhile.

Theme 2A: Characteristic of an Ideal PHR

Usability

Participants had other strong expectations about PHRs and characteristics they felt it should have. For one, they repeatedly expressed the importance of making the PHR *easy to use*. They referenced websites or systems that have persisted as benchmarks, such as Google and Facebook, and stressed the value of having a simple, user-friendly interface. For them, a PHR that was difficult to navigate or use would represent a major barrier to adoption: "If it's slightly challenging, or people don't feel that it's simple to use, or what the information they're putting in easily describes what they have, than that will certainly deter people." Conversely, a well-designed interface could actually motivate them to use it: "It sounds silly, but I'm sure that it's really important. Just make it attractive." A few participants cited Apple products as typifying these appealing interfaces. Since participants believed that using a personal health record required an initial, if not regular, investment of their time and effort, they wanted the interface for entering data to be simple to use and *streamlined*:

> "People are extremely impatient when it comes to using things. So it has to be as close to perfect as possible. Especially for something that is, you know, it's going to be a fair amount of effort to put this stuff in."

> "One thing for me that would be really important would be the ease of entering data. Because if it's like, if I have to go through a lot of checkboxes, and dropdown menus, and stuff like that… like auto-completion – I think on Google they had something like that? That would be really useful for here. …really make it easy, and really user-friendly."

Since many believed that the value of the PHR lay in its ability to connect with

other information systems, *common data standards* were identified as necessary, an extension of usability. Participants wanted to be able to easily transfer their medical record into their PHR:

> "[If] the hospital that I go to wants to submit the record directly, and I give them the permission, that they can do that because there's a common data format and then I don't have to think about 'how am I going to get my health record in the system?'"

Having data standards extended to the idea of a more lasting PHR system, as participants did not relish the possibility of having to re-input their health information into new systems:

> "I would be worried about the standard. It's like, okay - I spent three weeks of my time inputting data into Google Health, let's say. Google's not going anywhere, but let's say the Google Health system…is no longer supported by those clinics. What then? Do I have to re-input it into a new system? I mean, that would be more annoyance than end-game, but I think that would affect my ability to input. If I put it in once, I would want it to be transferable across systems."

Customizability and control over what is shared

Upon further exploration of this topic, participants determined that the PHR interface should not only be easy to use, but also *customizable* to suit the personal preferences and needs of the specific user. As one participant justified: "That's why it's a *personal* health record, and not somebody else telling you how to store your information." Another participant emphasized the importance of designing the PHR with the patient in mind: "It should definitely be designed from the perspective of the patient, and the patient's mental model… it would have to be designed for what they're looking for." Participants wanted to be able to tailor the PHR interface in order to display only what information or tools were relevant to them: "It should be customizable… so you don't get bogged down with everything that's on there." They also wanted to have control over certain features of the PHR, such as frequency of reminders.

The need to customize or control elements of the PHR extended to the information itself. Participants wanted to be able to decide *what information they*

shared, *and with whom*. One participant compared it to Facebook's privacy settings: "You know, like Facebook limited profile, something like that but for this health information." He further elaborated, imagining "tiers of information - and some of it more secure than others. Maybe, like, your lifestyle information is Tier 1, it doesn't matter who sees it. Tier 2, you determine what Tier 2 is, and then Tier 3 is strictly between you and this health professional." Participants agreed that it was important to retain control over exactly what they shared:

> "Customize your security, for each bullet of information you're providing, so that everybody knows, what's your blood type, lest you're in an accident, and that's the most important information they need to have. Allergies, everybody knows. …Some information can be public information, it has to be there. But then, with other information, you can customize things, like in your past history, what's your family history, things like that. So, every section you can have the control in your hands."

Users controlling what information was shared and equally what was hidden, especially from health professionals, could have ramifications, as pointed out by one participant: "So what if you keep your privacy, hide the information, they don't see that. That's just a risk you take, keeping it private?…They might get the wrong picture if they only get half the information." Regardless, most viewed control and customization as a way to address and ensure that there was a fit between the PHR and different user needs and preferences: "I'd be surprised if someone could design one tool that could solve everyone's needs. I think it would *have* to be customizable."

Cost

Though there were a few that felt "more comfortable paying for it," the majority of participants did not feel that they should have to pay for a PHR. As one participant explained:

> "We're used to having things that are accessible and free, and very simple, and going back to now you have to pay – since when? When's the last time you paid for, I dunno, anything online? Everything's free!"

In addition, since many believed that PHR use would increase the efficiency and benefit the healthcare system as a whole, they felt it should this would result in healthcare savings; this was seen as particularly true in the context of an

integrated PHR system that connected with other EMRs. Consequently, they felt that the cost of the PHR should be *borne by the government*, not the user, or should at least be subsidized in the form of a tax credit:

> "I think the system should pay it… I expect that, just people being more organized about their health, it would just create an economical benefit to the system. And then the government should take care of it."
>
> "If there was a tax credit, or something, it would be nice incentive."

Theme 2B: Use of PHR for Preventative Health and Lifestyle

Since participants considered themselves relatively healthy, they did not see chronic diseases and conditions as an imminent concern and still saw it as being far off in the future, "when you're fifty [and] you've got all those other things." In addition to using it as a comprehensive record of their health, they primarily saw themselves using the PHR, at least at this point in their lives, for preventative health and lifestyle:

> "It seems like the point of them is preventative. It's not going to diagnose you. So you don't end up with health problems later on, you can track and that's the benefit… If you see a trend of what is expected of you, and that's what it's monitoring, without making a life-changing diagnosis – that's what it's going to be good for."
>
> "I think that my ideal personal health record would have a prevention aspect. I think a lot of people tend to go to the doctor and expect them to fix everything, where a lot of the solution could lie in lifestyle changes. I think that could do a lot of good to the world."

One participant saw early adoption of a PHR as being a worthwhile investment for the future: "It seems like something that would be beneficial to start now, so we have it for our future, when things aren't quite as even-steven."

Tracking health and recognizing patterns

One key theme and expectation was the idea that the act of tracking could create awareness and help identify patterns in their life, and in turn help them make healthier lifestyle decisions, in terms of nutrition, exercise and stress. Participants believed that using a PHR could "force people to think more about their health":

> "I think someone who starts this process can be more conscious about his own health. If you start entering how much you slept, how much you

> weigh, it may be that you're going to find out things you have things you're going to have to change in your life."
>
> "That would be a huge part of it…as soon as you start tracking something, you become more aware of it. You know, even with regards to what you're eating. Like, it says 'oh my god, I ate donuts yesterday too and it's five times this week – I'm going to have to stop that sort of thing.'"

Though participants were healthy, they were also at the point in their lives where they were starting to think more seriously about how to maintain their health: "I'm 29, so I'm starting to think more about my health, in a more active way. Not doing enough about it, but thinking about it more." Awareness of what they were actually doing and the choices they were making was seen as the first step in helping them move towards what they *should* be doing:

> "We kind of know what we have to, but we don't know if we do it too, right? … I *know* how to eat well, and then how often do you sit down and *think* about what you ate this week… you can raise awareness of how below you're falling [in] your expectations, you know?"

Tracking health with the PHR was a way to help them recognize patterns in their life, and see the associations between things like diet, exercise and the effect they might have on their health:

> "There are so many patterns in our life, but we don't always realize, because we're not keeping a daily journal. This happened, and then this happened, you know, these things are connected in my life… you might start to make connections that you otherwise might not have."

Being able to track and see the relationship between lifestyle choices and their health could be motivating, and help reinforce those healthy choices. However, some participants noted that there could be a downside to tracking:

> "Maybe once you start tracking, you might get a little paranoid…you might freak out, and go to the doctor all the time, and be 'I have this.'"
>
> "It could be demotivating. You can see yourself on the decline, and like, I don't think I'm going to have this. …You see yourself on the decline, and it can affect you."

Comparing to the norm

Participants expressed a desire to use the PHR to compare or rank themselves against the "average" or a norm: "It would be to compare my health, or some aspects of my health with what the average is, as a preventative thing." By having

a standard to compare themselves against, they could also set targets: "You compare yourself with a standard… here's the average for 20-whatever year old. It would be cool if you also could maybe set some targets… I think it would help motivate me a little bit if I said – oh, there's my target."

Understanding hereditary influences

Participants exhibited an awareness of how hereditary factors could contribute to health, and several expressed the desire to use a PHR to gain a better *understanding of their own family history*, and in turn be able to pass their information on to future generations. Becoming aware and informed of genetic susceptibilities was expected to help guide better choices to prevent future illness:

> "I'm adopted, and when I try to access information about my family, I wasn't allowed to. I wasn't even allowed to have access to my own personal information, so at least keeping track of my own, and then I can pass that down to my children, so that they could kind of determine whether they are at higher risk of being exposed to certain things with their health."
>
> "[The] other selling point [is] if you want your kids to know what you're about, since you were a kid, it's good to have, because… you don't go and ask 'is diabetes in the family?' Then if you find out, then it's too late, and you know, you couldn't have done any preventative measures."

Theme 2C: Taking More Control of Their Health

Increased independence and autonomy

Some participants expected that using a PHR would enable them to take more responsibility and control of their own health and health information. In one case, a participant felt it was becoming a necessity as he transitioned to adult care:

> "I mean your parents pretty much take care of all of this, when you're a child, or even a teenager, right? And in the last few years, I've been getting really health conscious, and my doctor would ask me 'have you been vaccinated for this, have you done this?' and I have no idea… If we can be in control of our health information, instead of it being [something] that we have no real understanding or control over. I think it would be really good for peace of mind for people to be able to control their own medical information."

One participant saw the PHR, and the Internet in a more general sense, as tools that could allow her to independently "double-verify" decisions made by her

healthcare provider, so as to not blindly trust the judgment of the physician:

> "If you have these records transferred from your physician, then at least you have the empirical evidence that they're basing their decisions on… Even though they don't have medical training themselves, there's a lot of self-educating that people do. Because we have Internet now, we don't go 'oh yes, physician, we'll do whatever you say'. We always go home and look it up, we want to know about the things that we do…We do trust our physicians, but at the same time we want to be the police of our physicians."

One participant agreed and saw the PHR as being a path to increased self-reliance and independence from the healthcare system:

> "A lot of people that go to doctors or utilize medical services totally rely on the physician and their opinion and their information. But having that knowledge and awareness, you won't have to rely on them so much."

At the same time, there were others that expressed hesitancy about the idea of increased responsibility over their health, feeling that "it puts lots of responsibility on the patient."

Avoiding care through self-diagnosis

In terms of how they *themselves* expected to use the PHR with respect to getting healthcare services, participants mainly focused on the idea of *avoiding care*, rather than improving care. The majority of participants wanted to be able to avoid going to see the doctor, unless deemed absolutely necessary – largely due to the time and effort they felt it required to do so, which was seen largely as a waste of time. Many expressed frustration in their experiences trying to access care, whether it was the difficulty making appointments with a doctor, or waiting hours to see a doctor. Even for those who had a regular physician, some were disappointed with the quality of care they received:

> "My doctor switched offices just recently, and I've been seeing him for, I think five years. And I show up at his new office, it's at a clinic, or whatever. And I show up, and he didn't even know who I was. He couldn't find my file, he didn't know why I was there… and he's trying to, like, guess. And it was awful… I was so disappointed with that appointment."

As a result, many felt it was best to circumvent seeing the doctor altogether, and looked to the PHR as a way to facilitate that. A major way they envisioned using the PHR to avoid visits was through self-diagnosis. Many already used, or knew

peers that used the Internet to self-diagnose their symptoms or conditions:

> "My friends, I find, if they feel bad, or they have something weird, they Google it. Instead of going and meeting with a doctor, they'll Google it."

> "Going to a doctor here, it takes a long time. I mean, especially if it's not something not even vaguely life-threatening, it takes forever…So it's a lot easier to Google it and say 'oh, that's it, it's not super-invasive, maybe I'll try doing this instead.'"

> "I would do that before I would bother going and waiting in a clinic for four or five hours, which I think is ridiculous. I would always check things online first, before I go to a doctor."

However, other participants felt that self-diagnosis might encourage people to focus on the negative, and even be a source of stress itself:

> "I think that there's a really big trend towards people always thinking that something's wrong with them. I'm not sure whether this kind of product would make you think more about what's wrong with you, or keep track of the healthy things you're doing…by focusing on all the bad things we might have happening in our health lives, I think we might become more hypochondriac."

> "It's almost dangerous when you start looking up information by yourself. Just the stress alone that it causes, just by diagnosing yourself, it's gotta be bad for your health."

They did acknowledge that there were risks with assessing or taking action without proper medical judgment and worried that people might "not fully understanding the information and making mistakes that would change [or] damage [their] health."

> "I'd be more concerned about the self-diagnosis thing… I kind of worry that that might end up being a problem in that people would be trying to take too much control over it, but not really having any information about what's actually going on."

Reputable health information

Despite the risks of self-diagnosis, most participants wanted to find alternatives to having to go in to see a doctor, so it was also thought the PHR could potentially provide more relevant or authoritative health information resources for patients:

> "Providers could probably put information there that's more reliable than whatever you find on the Internet. It's hard if you want to educate yourself, but you don't know which websites are better, so that could be a way to help patients go, for some that don't know it – more efficient."

The information, however, should be easy to understand for the user, and presented with the user in mind, not the physician: "So that the information is not only presented to my doctor, but to me in a way that I can use it. Because I'm much more likely to participate if I'm likely to use it, rather than just the doctor."

Theme 2D: Making the PHR Worthwhile

Making it worth the time

Despite the potential benefits offered by the PHR, both on a theoretical and personal level, some viewed tracking and using the PHR as a waste of their time, and did not consider it to be worth the payoff unless they were actually sick:

> "I don't feel any need yet. I don't see a doctor regularly or anything, so I would just be spending useless hours filling in things at this level. I probably wouldn't use it, until I have some kind of condition."

Many participants expressed concern that maintaining their data in a PHR would be too time-consuming as they felt there were already too many demands on their time: "We already have so many things to do!"

> "You go to school, check Gmail, and then you check Facebook, and then you check banking, and then you check bills, and then by the time you actually sit down to do something, it's lunchtime. It's just another thing. So I think that it would be hard to get over that for me."

Since participants placed the value on having accurate, continuous information in the PHR, to them it implied a consistent, regular input of information (and effort) on their part for it to be worthwhile:

> "I wouldn't be apt to plug in my own personal information if I was sick, in general. I would not have the drive or want to do it. And then preventatively, there's nothing wrong – why would I need to do this now? I would be that lazy person that would have probably initial comments, for the first month of having it, and then I wouldn't do it again until I either got sick or finally started to feel better, having been sick."

With so many other obligations and things to do in their life, some believed that health would simply not be a priority and would consequently not be worth the time needed to input data into the PHR:

> "If I was really busy with my life, with work and other stuff that I do, I would probably not focus on health, and therefore it would not be useful at all. I would not want to spend that much time entering data into it."

However, some felt that they would be more willing to invest the time if it interacted with their physician and offered the possibility of getting an answer:

> "Maybe if you have more advanced [PHRs], where you can get feedback from a physician or something, then you would have an incentive to track, because then you know that you'll get a possible answer."

Furthermore, since time was considered a valuable commodity, the majority agreed they would likely use features of the PHR that would save them time:

> "Instead of going to see the doctor to get the prescription renewed, it would save a lot of time and money if you could just click a button and say 'I want my prescription renewed' and the doctor would send it to the pharmacy."

> "It's really hard to get in touch with a family physician or anything, so making appointments… online would be really fantastic."

Providing interactivity and reward

One recurrent topic was the idea of interactivity, or *getting some kind of feedback* from the PHR. Participants wanted to see their data in the form of some sort of visual representations of the data, whether it be graphs, charts, and believed that it could help them gain a better understanding of their health. They also wanted their PHR to provide useful reminders and envisioned a system where "you could choose your own reminders," whether it was for medications, to make appointments or checkups, or to enter data into their record. However, there was "the positive side of the reminders, and the negative side of the reminders." This idea of the fine line between positive and negative feedback was extensively debated. On the one hand, many believed that a system that was inherently reinforcing would encourage them to use it regularly for preventative health.

> "And some way, it should, relating to…prevention and positive reinforcement, [have] some kind of way to improve people's habits, that's actually based on psychology that works. I mean, there are so many sites that will nag you… and then everybody uses them for a short period of time, and then stop. [It needs] some way to actually engender long-term habit changes in people."

Participants went so far as to desire a sense of reward for using the system: "Would we want to do it, and do we do it regularly? So the idea [is], it's an incentive system, I want it to reward me for doing it. I clearly can't provide my

own rewards." However, they were only interested in using the system so long as the feedback was positive, as one participant admitted: "It has to make me feel better about myself." If the PHR reminded them that were not in good health, or were not making good lifestyle choices, they would be less motivated to use it, as it would discourage them or make them feel guilty:

> "So maybe if I wasn't walking to work, or eating five vegetables a day, or whatever this computer program was telling me to do, I would probably just turn it off. And then I probably wouldn't go on it, because every time I would go on it, I would feel guilty."

Many participants proposed that notion that introducing games or applying game psychology to preventative health within the PHR could be an effective way to motivate them and others to use it while avoiding possible discouragement:

> "If I can monitor my food, my exercise, and it can all be presented in a game, like a video game format, I could definitely get into it… [because] the idea of game psychology, is that it's set up so that you're not discouraged at any point. It's addictive. You're only rewarded. And you're rewarded at specific intervals to keep you interested, you know. But it's never hard enough that you're just going to want to turn it off?"

Overall, though there were a few participants who had no interest in using a PHR, as they felt that there were "too many cons, versus the pros", the majority of participants saw that using the PHR could be beneficial to them, and were interested in trying it. Ultimately though, they believed that if the PHR did not "really [serve] the point you wanted it to" or the benefits did not merit the investment of time and effort, they would stop using it: "I would use it, but after awhile I find out that it's not worth it, I could just drop it. But I would definitely try it."

DISCUSSION

With PHR research and development still at its inception, our findings contribute valuable information to the ever-growing and much-needed knowledge base on PHR adoption. While previous studies have looked at older users and the chronic disease population, this study focused on the views and expectations of young healthy adults. Results revealed that when thinking about the PHR *itself*, participants identified the same potential benefits voiced by patients and other stakeholders, despite being young and healthy. Though their generation is apt to share many personal details of their lives on the Internet, participants also expressed similar concerns about privacy and security. What was striking was how the focus and motivations changed when participants considered how they would *personally* interact with the PHR. Their prior experiences with technology, the health care system, and their perception of their health played a big role in determining their individual expectations about using a PHR. The resulting expectations stood in contrast to what has been seen in the literature, and point to future avenues and applications for PHR development and research.

Views on Personal Health Records

Perceived benefits of the PHR

When considering the PHR on a more theoretical level, participants pinpointed several potential advantages, including being able to bring together parts of a fragmented health record all in one place and creating a comprehensive and accurate record of health information. They believed that this in turn would lead to better treatment decisions and safety by giving a more complete picture to their healthcare provider. Participants also stressed the value of an integrated system, otherwise they felt the PHR would simply function as an electronic repository, which held little value to them. For participants, the act of putting information online *necessarily* implied greater connectivity to people and information systems. This push towards integrated PHRs has likewise been emphasized by other stakeholders, including by the Markle Foundation, which has advocated that future PHRs *must* be able to be integrated with a standardized, interoperable

network of EHR systems.[18]

Participants also saw the PHR as being able to improve care, but considered it more from the perspective of the healthcare provider. Discussions focused using the PHR to alleviate the already overburdened Canadian healthcare system by increasing efficiency of administrative and clinical processes. Though participants proposed using the PHR to help prepare for clinical visits, they envisioned it being used by the *physician* rather than the *patient,* as opposed to what was seen in other studies.[41] Participants also spoke of improving health system efficiency by prioritizing care or reducing unnecessary visits. These views and the emphasis on making the most of overextended resources reflect an awareness of the challenges facing the Canadian healthcare system today, including overcrowded hospitals and difficulties with access to timely care.[44,120-122] Participants also emphasized *accessibility* of health information, particularly with respect to moving around and travelling. Given that relocation is quite commonplace, especially within this age group, this was a new dimension of accessibility that will be important to consider in the future. Correspondingly, new PHR options are emerging in the market – for example, PHRs developed for mobile devices (smartphones, cellphones, tablets) were recently highlighted in a report by Deloitte as a new PHR opportunity.[123]

Another potential advantage or application of the PHR that had *not* previously been identified by PHR users in the literature was the notion of aggregating user-generated PHR data for research purposes and using it to analyze population-level trends and associations. While a popular notion with researchers, this was also consistently brought up across focus groups, with Google Flu Trends sometimes used as an example. This result was somewhat surprising as it stood in contradiction to concerns about security and confidentiality. It suggested that participants did not feel a strong sense of ownership over their data so long as it was anonymous, and desired that the information be used for the greater good.

Potential users and their characteristics

In terms of who they envisioned as potential PHR users, participants seemed to believe that it was *their* generation that would be more likely to adopt this type of technology. Moreover, despite it being more beneficial to individuals with chronic illnesses, they suggested that healthier and more educated individuals might be more likely to use it. This echoes the findings from Weingart et al, which found that enrollees for a PHR offered by a clinical practice were more likely to be younger, healthier and more educated.[60] Consumer surveys seem to support this notion, and found that younger individuals were more interested in using a PHR than older individuals.[68] Participants also mentioned caregivers, which may be a consideration to them as their parents are now getting older. Interestingly, though participants expressed skepticism about access by older or less computer or health literate individuals, neither race nor ethnicity was raised as a potential issue.

Concerns about PHRs

Participants expressed many concerns about PHRs, especially with respect to the misuse of personal information. Privacy and security concerns mirrored those found in other populations, such as a 2006 Markle report which found that the main concern with using PHRs was the potential misuse of personal data by marketers (77%), employers (56%) or insurers (53%).[68,75] However, Weitzman concluded that 18-35 year old focus group participants did not consider the potential consequences of sharing information. Our results suggest the opposite is true. While young adults do share considerable personal information online, coining the term "oversharing", they distinguish health information as being more sensitive in nature and are therefore more reluctant to put on the Internet, for fear of what might happen as a result. The level of sensitivity of specific information is inversely associated with a person's willingness to share that information.[124] Concerns about the misuse of information may not be completely unfounded. An inventory of existing PHR websites in 2009 found that most PHR sites did not state their intent on secondary uses of personal health information, and one-third had no reference whatsoever to protecting data.[49]

Participants had other concerns about PHRs. For one, they stressed the hypothetical consequences of confidentiality being compromised, such as in cases where one might be stigmatized or discriminated against (e.g. HIV, mental illness). Focus groups with older users[94] also brought up the idea of stigma and discrimination, though not as extensively. Interestingly enough, it was older users in this study that felt that they had "nothing to lose" versus participants in our study, who felt that they currently had "nothing to hide." In short, despite the fact that this self-described "Facebook generation" uses technology on a daily basis and is accustomed to putting personal information online, they still harbour serious reservations about putting sensitive health information on the Internet. However, they were simultaneously cognisant of the fact that these issues could likely be overcome, especially if sufficient demonstrable benefits are offered, as evidenced by their example of online banking. Interestingly enough, the majority (96.6%) of participants reported using the Internet for online banking, substantially more than the 67% reported in the general population,[27] suggesting that these concerns are not insurmountable.

Another misgiving expressed was that data generated by users in the PHR might create information overload, both for the patient and the physician. Young adults are accustomed to producing user-generated content online through systems such as YouTube. In spite of being contributors to online content themselves, they recognize that one of the pitfalls of information on the Internet is that it can be difficult to extract what is most pertinent. Access to greater *quantity* of information does not necessarily equate to better *quality*. Participants also collectively addressed other salient issues, such as the challenge of maintaining data integrity, capturing the complexity of health information in an electronic format, and how PHRs might affect the balance of power and responsibility between patients and physicians. Though these issues have been debated within the literature,[50,74,125] participants demonstrated a surprisingly sophisticated and comprehensive awareness.

An equally interesting finding was what was *not* mentioned by participants. Participants did not bring up identity theft or fraud, which was found to be a dominant concern in the 2006 Markle report.[75] Another notable omission was the discussion of who would "own" the data. It was not clear whether this was because participants assumed they would own the data or whether they assumed that once information was put online, regardless of whether it was user-generated or not and irrespective of who was sponsoring the PHR, it was "out there" and therefore could not be owned.

In summary, findings confirmed that young healthy adults perceive similar benefits overall and share the same privacy concerns as other groups studied in the literature. However, there were a few subtle differences in their views compared to what was previously reported, including accessing of health information for travel and moving, compiling anonymized data for research, and the idea of information overload. Our findings also contribute to the ongoing debate as to whether healthy individuals, or the "worried well" may be more likely to use PHRs. Lastly, the way in which participants envisioned how PHRs could improve health care provided new perspectives and attitudes about PHRs that seem to arise from the specific Canadian healthcare context.

Expectations about Personal Health Records

The focus and emphasis began to shift once participants began to consider how they *personally* saw themselves using a PHR. While some themes corroborated current evidence on factors affecting PHR adoption, particularly with regards to usability, new insights emerged as to the expectations about using PHRs that had not been identified or stressed in previous studies.

Characteristics of an ideal PHR

In outlining what characteristics they deemed necessary in an "ideal" PHR, participants stressed the importance of a PHR that was easy to use and customizable. Usability has long been considered a crucial element for adoption

of information technology.[63,97,126] Since PHRs are patient-driven, having a system that is easy to use becomes even more essential for uptake; however, the nature of the PHR poses specific challenges. In a report on the evidence base for PHR usability, Marchioni (2007) argues that PHR systems are inherently complex because health *itself* is complex and healthcare involves many different people and organizations.[97] Furthermore, health information is also very complex, more so than other types of records (e.g. financial) that are typically managed in one's life. Despite these challenges, personal health information is *relevant* to everyone regardless of age, health, socioeconomic status or computer literacy, so systems should be designed to be usable to many people. Marchioni goes on to propose that "in the early stages of PHR development, the usability solution for the complexity and universality posed by PHR systems suggests *customization* paths for users… it is likely that people will bring very different needs, experiences, demands and expectations to their encounters with PHRs." Though Marchioni believes that customization is particularly important for older users and people with specific chronic health conditions, our findings suggest that customization is equally if not *more* important for younger and healthier users. Since they are not using it to actively manage a condition but looking to use it for preventative health, they want the PHR to be easy and simple to use. Moreover, they want to be able to tailor the interface and functionality to their specific needs. This expectation of usability and high degree of customization is in part due to young adults' experiences with existing technologies, such as Google and Mac products. In general, their expectations of a new or prospective technology like the PHR were grounded in their experiences with existing technologies, especially ones that they used on a day to day basis. Namely, systems such as Facebook or Google were referenced and used as "benchmarks" for what they expected from the PHR. For example, the need to have control over exactly what elements they shared and who they shared it with was compared repeatedly to Facebook's privacy settings. Google was used both as an example of clean, simple interface design, but was also used as an example of how information can be mined or used for more directed advertising. As a result, young adults expected to be able to do,

at a minimum, the same things *if not more* with a PHR as they do with existing tools. Some could not conceive of a "one-size fits all" system that was *not* customizable to their preferences. If PHRs are to be used in the future by this generation, these findings support and reinforce the importance of designing usable, customizable PHR systems.

Participants were equally accustomed to not paying for services on the Internet, and were equally uninterested in paying for a PHR. This conflicts with findings from Adler,[77] which suggested that patients of all ages would be willing to pay a small annual fee. However, it supports other results, which found that diabetic patients were unwilling to pay for a PHR.[78] Our findings also contribute an added dimension to the question of cost. Participants felt that PHRs should be subsidized by the government – this expectation of government subsidies or tax incentives may be unique to universal healthcare systems such as Canada's, where the cost of health care is not borne solely by the individual.

Using the PHR for prevention

A significant finding was the *way* that young healthy adults expected to use a PHR, as compared to what has been described previously: participants primarily considered the PHR in the context of preventative health. Since previous studies have focused on older adults as well as chronic disease patients, the potential application of PHR in prevention has not received a great deal of attention. Young adults did not consider themselves at the point in their lives where they had to worry about chronic diseases or complex conditions. They saw these problems as still being in the future, with 50 years old being a consistently mentioned milestone. Instead, participants expected to use the PHR to play a role in maintaining good health. Moreover, young adults exhibited an awareness and recognition of the role of lifestyle choices, such as diet and physical activity, in maintaining good health and preventing illness. Accordingly, they saw the PHR as a way to help keep track and become aware of these choices and how they impacted their health. Participants also acknowledged that there was a distinction

between *knowing* what you are supposed to do to stay healthy, and then actually *doing* what you are supposed to do. Several participants positioned themselves on the crux between knowledge/intention and behaviour, and surmised that tracking through the PHR might facilitate this transition in a few ways. First, they expected that the PHR could help them learn or understand what they *should* be doing, by providing reputable and up-to-date health information resources, guidelines, targets and facilitating the ability to compare themselves to their peers or the average. Secondly, participants expected and stressed the ability of the PHR to help them become aware of what they were *actually* doing, to become more conscious of choices that they might be making in their everyday life that needed to be changed. Lastly, they spoke considerably of the PHR providing reinforcement or reward in such a way that it would not only encourage them to continue tracking, but also encourage them to keep making positive lifestyle choices. This sense of ongoing achievement and motivation was considered crucial in having the PHR be used to encourage preventative health. Another unexpected finding was the consideration participants gave to understanding and becoming aware of patterns in their family history and hereditary influences. Participants saw this information as being an important aspect in their perception of their health and health risks, and integral in deciding what steps they would take to maintain their health.

Taking more control

The literature has promoted the idea that one of the major benefits of PHRs is its potential to increase the involvement of patients in their own care. Our results support the idea that young adult users similarly expect the PHR to increase self-management in their own care. In conjunction with the trend of seeking health information on the Internet, some participants saw the PHR, and the Internet as a whole, as a way to independently verify decisions made by their physician. Access to information was seen as a way to decrease the dependence on the physician's judgment. In addition, some were concerned with the idea of more ownership and responsibility. The study by Weitzman likewise found that

participants valued the increased autonomy and control of health information, but also worried about bearing the responsibility that they felt went with that control.[94] However, young adults not only envisioned the PHR as a way to have more ownership in their health, but also as a means to become increasingly *independent of the healthcare system*. The majority of participants expressed considerable frustration with the healthcare system and issues with access to care or quality of care. Though they simultaneously recognized that it was due to the limited resources of the healthcare system, participants were discouraged by long waits and difficulties seeing a doctor. In fact, only one-third had a regular physician in Montreal, and one-third did not have a regular doctor whatsoever. Issues with access to care motivated them to look to the PHR address these issues, by either improving the efficiency of existing services, or largely as a way to *avoid care altogether*. Participants expressed the desire to be able to contact their doctor electronically, but rather as a way to confirm whether it was necessary to see them in person; when possible, they preferred to avoid unnecessary visits and the associated waste of time. Many young adults already used Internet to seek out health information, or to "Google" symptoms, and as a way to self-diagnose as opposed to seeking out the opinion of a medical professional. In fact, some considered it a preferable first step, before investing hours in a waiting room. Even though they recognized potential dangers and pitfalls of Internet self-diagnosis, they preferred it as an alternative to scheduling a medical visit, and therefore wanted the PHR to serve as a source of more relevant and authoritative health information. Consequently, they wanted this information to be presented in a way that they were most likely to use: clear, easy to understand and free or medical jargon. However, the idea of the PHR as an *alternative* to care brings up some significant questions. Surely, while increased awareness and ownership of health is beneficial, there is a point at which this increased independence might be detrimental. PHRs may facilitate individuals in avoiding appropriate and necessary care. As argued in the 2003 Markle report, "simply offering people a means of recording information on a daily basis does not make them better managers of their health and healthcare. Without a clinician on the other end of

the application continually providing advice, making modifications to prescriptions or otherwise providing them with some ideas to help them better manage their condition, these systems were doomed to fail."[18]

Making the PHR worthwhile

Another theme elaborated was the challenge and suggestions as to how to make the PHR worthwhile to users. While the perceived burden on time and effort has been discussed as a barrier to HIT adoption in the professional and organizational context,[70,127] these results suggest that it is equally important in systems geared towards the patient or consumer as the end-user. Having grown up in the information age, young adults are faced with the increasingly fast-paced demands of modern life. Many participants spoke of already feeling pressured or burdened by existing commitments, and had no interest in adding another obligation. They only saw it as being useful if it in turn provided some discernable advantage, either through convenient time-saving features, or through instantaneous feedback. The importance of interactivity and reward has not yet been explored in existing PHR literature. This may be an issue that arises directly from the fact that this study focused on young healthy adults. However, as PHRs continue to develop, the target audience will grow to include these individuals, so it is worthwhile to consider this matter early on. Young adults are used to interacting with technology and using it beyond a functional pragmatic level. Technology is part of their leisure and games were repeatedly stressed as a benchmark for how PHRs for prevention could be made more appealing. It suggested that a sufficiently motivating system might be able to provide the impetus to translate *knowing* into *doing*. And though the need for interactivity and reinforcement is particularly important when PHRs are used for prevention in healthy individuals, this does not mean it should be limited to this context. This finding suggests exploring ways to make the PHR reinforcing and rewarding in order to encourage lasting, long-term adoption.

In summary, what healthy young adults expected from using a PHR for

themselves contributed new insight into different ways that PHRs might be used. For instance, instead of *managing* disease, PHRs could be used to help *prevent* disease, especially in users that still have the opportunity to make necessary changes to improve future health outcomes. Young adults also saw PHRs more as a way for them to avoid contact with the health care system. We found that anticipated use of PHRs in preventative health, independent of the healthcare system, necessitates designing systems that incorporate positive reinforcement and interactivity to make it worthwhile and motivating enough for the young adults to use it.

Other Findings

As outlined by the 2003 Markle report,[18] one of the major challenges to PHR adoption is the lack of widespread awareness, and this continues to be an issue. The majority of participants had never heard of a personal health record. In the pre-interview questionnaire, one-third of participants responded that they had heard of a PHR. However, following the presentation on PHRs, most of those admitted that they had very limited knowledge about PHRs, or had actually confused the personal health record with the electronic medical record. This finding was unsurprising, given the relative scarcity of PHR products available in Canada, as compared to the US. A European study similarly found that Austrian and German citizens were largely unaware of PHRs, and none of the respondents had ever used one.[76] Even in the US, where there are more commercially available PHRs and payer-sponsored systems, a 2006 consumer survey found that only 17% of Americans (n=1 095) had used a paper or electronic PHR, and the primary reason for not using one was because they had never heard of a PHR (52%).[128] Educating the public and creating awareness about PHRs may represent an important priority. Given that awareness and familiarity with PHRs was limited, focus groups were a useful mechanism for generating discussion. Since few participants had used or knew of PHRs, the views and ideas expressed truly emerged and evolved as a result of the discussion and interaction between participants, in conjunction with the information provided in the presentation.

Limitations

There were several limitations of this study. For one, this study focused on young adults but eligibility was restricted to participants fluent in English and therefore may not have explored issues relevant to young adults not comfortable with English. Participants were quite educated and their awareness of technological and theoretical issues may not be representative of their age group as a whole. Though participants ranged from 18-34 years old, the majority (79.3%) were between 25-34 years old. It has been suggested that there may be "mini-generational gaps" in the way that young people use technology,[129] that the tools and the way in which an 18-year old uses technology might be quite different from that of a 30-year old. So though this study considered young adults as anyone between the ages of 18 and 35, some differences and subtleties may exist within this group. Secondly, focus groups, while useful for generating a wider breadth of information, are a "social" environment, and therefore can sometimes be less useful for accessing in-depth accounts of marginal opinions. One focus group was smaller than generally recommended (four participants, as opposed to the suggested minimum of six) due to scheduling difficulties and last-minute conflicts. However, it did allow participants more time to respond and reflect on what others in the group had said. Despite the group dynamics, since participants are not singled out specifically to respond to questions, focus groups can still provide a safe environment to discuss topics and also serve to diminish the role of the researcher. Another potential limitation was that data collection, coding, and analysis were carried out by a single individual (the author). Though this allowed for a greater familiarisation and understanding of the data, the resulting descriptions would depend on the perceptions and sensitivities of the describer.[109] To minimize this tendency and improve the integrity of the findings, the results and analysis were reviewed on an ongoing basis with the research team.[130] Lastly, though sampling aimed to maximize variability, participation in the focus groups was voluntary; therefore, there may have been an element of self-selection. Nonetheless, the findings of the study have generated new information that will provide an important basis for future research in this critical area.

Understanding the Canadian Family Medicine Context

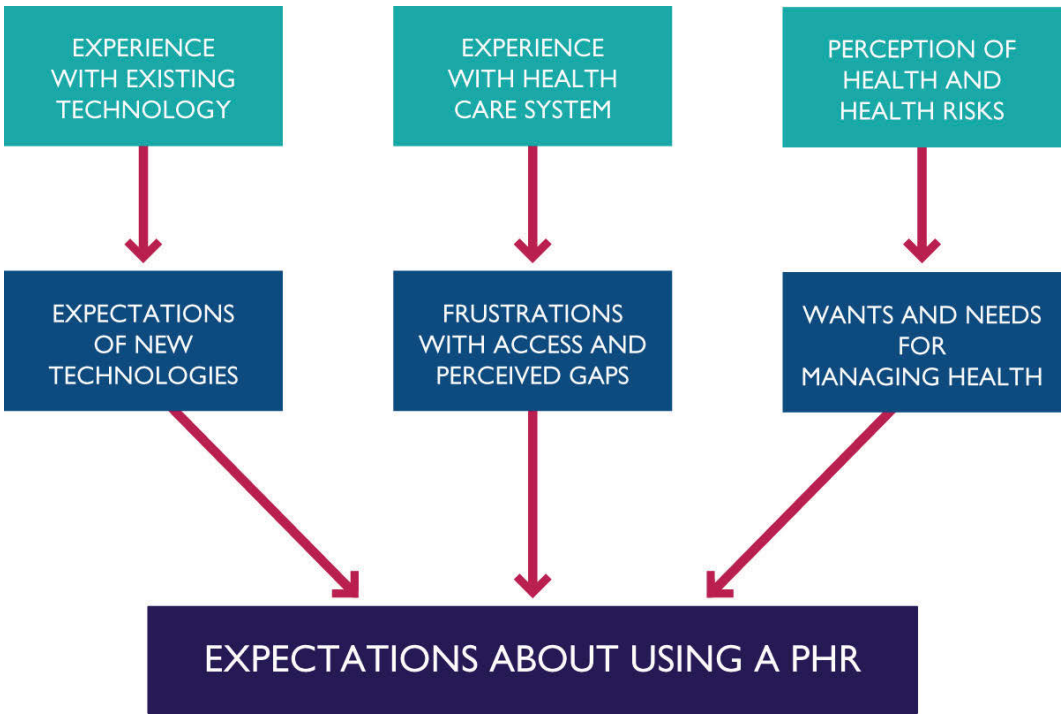
Although not necessarily a limitation, it is important to note that most PHR research and development has been done in the US but this study suggests that there are considerations that are unique to the Canadian healthcare context. Expectations of this technology seem to be impacted by users' experience with their own healthcare system, in combination with other factors. Accordingly, for PHR implementation to be successful in Canada, future research should further explore the specific expectations of different populations of Canadian users. A recently published qualitative study examined the perspectives of Canadian family physicians on PHRs and found that physicians expressed similar concerns as those brought up by our participants.[125] This included the potential for misinterpretation of medical information, the effect on the patient-physician dynamic, an increase of workload, and a lack of clarity surrounding the physician's responsibilities with respect to the PHR. They also brought up issues of data guardianship, especially as one of the few widely available PHRs (Google Health) in Canada is owned and operated by "private companies with no direct role in the patient's care."

Family physicians did not support the idea of email or messaging replacing face-to-face contact, and rather felt that there would necessarily have to be an *increase* in patient-physician communication to adequately explain details if patients gained access to their EMR through the PHR. This finding was particularly interesting as it conflicted with what participants in our study wanted, which was to *reduce* in-person visits and contact with their physician through the PHR. However, they ultimately came to similar conclusions on what was needed: an integrated PHR system that was easy to use and not a burden on cost or time that demonstrated added value to the user.[125] Other studies looking at family physicians' perspectives have reported similar findings.[70,127] Exactly what that added value is depends on the population being targeted, and more research is needed to understand the views and expectations of all potential PHR stakeholders. Clearly, there are still many issues that need to be considered and addressed before moving forward with PHR implementation.

Conceptual Framework

These results corroborate previous findings on the perceived benefits and concerns about PHRs. This study also contributes new evidence on what a specific population, young healthy adults, *expect* from using such a system. In this respect, the richness of the material generated warrants further elaboration and interpretation. I therefore propose a conceptual framework that identifies factors influencing expectations of young healthy adults about using online PHRs (see Figure 1 below).

Figure 1: Conceptual Framework of Factors Influencing PHR Expectations



Within this framework, expectations of personal use of the PHR are influenced by three factors: experience with existing technology, experience with the healthcare system, and perception of health and health risks. Participants referenced systems they already knew (e.g. Facebook, Google) as indications as to what they could and did expect from PHRs. This pertained mainly to issues of usability, customizability, as well as the expectations that the PHR could integrate easily with other information systems. Prior experience also led them to expect that the

same level of accessibility of information as they were already accustomed to with other systems. For example, they surmised that they should be able to access their PHR through their Internet enabled cell phones, since so many other applications were already available through that venue. Secondly, the individual's experience with the healthcare system shaped their expectations about using a PHR as well. Frustrations and difficulties with access and getting the care they sought led them to see two possibilities for using the PHR: as a way to improve the efficiency of existing health care services, and more significantly, as an alternative to care. Participants expected to use the PHR to minimize the need to seek care and circumvent the healthcare system altogether, through self-education and self-diagnosis. Lastly, the individual's perception of their health and health risks influenced their personal needs for managing their own health. How they considered their current health, in conjunction with predisposing hereditary factors, determined to an extent what they felt was important in terms of health at that point in their lives. In the case of young adults, this led to the primary expectation that PHRs would be used for preventative health, rather than disease management. This framework provides insight into factors influencing expectations of PHR use, and represents an important step towards understanding and overcoming barriers to PHR adoption.

Conclusion

This study explored the views and expectations of young healthy adults about using a PHR, and revealed that what they perceived as benefits when considering the system as a whole did not necessarily equate to what would motivate them *personally* to use it. On a theoretical level, young adults generated and identified similar benefits and concerns to what has already been seen in the literature. Despite being a generation with different notions of online privacy and sharing, we found that participants still exhibited strong awareness of potential privacy and security concerns, especially with regards to health information. However, the expectations they had from a personal level about using a PHR illuminated new considerations. In fact, these differences may be precisely *because* this population

is young and mostly healthy. Their primary motivation is not to manage or track an existing health condition or illness. Instead, they see the PHR in terms of preventing illness and promoting wellness and positive lifestyle choices. Since the consequences of not tracking or using a PHR is less severe, and with time as a valued commodity, it suggests that a more significant barrier to adoption in this group is the time and effort required to maintain information in the PHR. Therefore a greater sense of inherent reward and motivation has to be provided by the PHR to encourage initial uptake and ensure long-term usage. Based on these results, a conceptual framework was proposed that outlined factors influencing expectations in this population. These findings provide new insight into how issues may vary in different populations, and point to possible causes of low adoption rates. Adoption may hinge more on the fit between the PHR and the individual's personal expectations and anticipated use, rather than on the perceived benefits of such a system.

In fact, much of current enthusiasm about PHRs has focused on its anticipated benefits. However, what this study suggests is that more research is needed on its *anticipated use*. In other words, how do different populations of users expect to use such a tool and what do they want and need from it as a result? Regardless of whatever potential benefits are expounded by policymakers, stakeholders, and even by users themselves, actual adoption may rely on having a better fit between the technology and user expectations and anticipated use of that system. This may be especially true with a patient-driven system such as the PHR. Possible avenues for exploration that were touched upon by participants include: considering hereditary and genetic influences in context of prevention and health IT; looking at new ways to use IT to engage young consumers in their health; exploring the differences between healthy young adults and those with a serious health condition; and exploring or incorporating new interactive mechanisms, such as games, to encourage long-term adoption of these systems. In fact, research has already begun to explore some of these possibilities. Seven NIH-funded trials were announced in November 2010 that will use technology, such as Internet, cell

phones and social networking, to prevent weight gain and promote weight loss among young adults ages 18-35 through healthy eating and physical activity.[131] As Canada moves towards implementation of a nationwide EMR and eventually an integrated PHR, research should examine how issues influencing adoption are similar and different in the Canadian healthcare context versus other settings. Finally, it also emphasizes the critical importance of ensuring and testing usability of future PHR systems.

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APPENDIX 1: LITERATURE SEARCH STRATEGY

To review the relevant literature on individual-level issues affecting PHR adoption, a search strategy was designed to capture and identify all applicable articles relating to views, barriers and facilitators to personal health record adoption from the patient/user perspective within the empirical evidence. As the term "personal health record" is relatively new and continues to evolve, there are other concepts, terms and tools that may capture the functionality of a PHR without necessarily being referred to as such. Furthermore, as some PHRs exist as an extension of the electronic medical record, there could be overlap with respect to the terminology as well. Consequently, a list of related concepts, terms and synonyms was conceptualized (see Table 1.1) and a search strategy was then revised to better capture potential synonyms as well as to be more specifically tailored to answer the review question.

The resulting search strategy (see Appendix 1.2) was used to search the following electronic databases: MEDLINE (1950 – June Week 2 2010), EMBASE (1980 – 2010 Week 24) and the Cumulative Index of Nursing and Allied Health Literature (CINAHL). Limits included English language papers, papers published after 2000, and human studies. This search was repeated in November 2010 to include newly-published articles. The 2008 ISI Web of Knowledge Journal Citation Report was consulted to identify the top journals in the field of medical informatics, based on their impact factor. The Journal of Medical Internet Research, Journal of American Medical Informatics Association, Medical Decision Making and the International Journal of Medical Informatics Association were hand-searched to identify any literature that had not been captured in the database search. Additionally, citation tracking or snowballing was used to identify additional references citing or cited by key articles and review papers through SCOPUS, and personal files were also included.

References were managed using Endnote X2 Reference Manager software. Only primary studies examining or evaluating individual-level barriers or facilitators to adoption of PHRs from the patient perspective were retained, either directly (eg. evaluating attitudes towards PHRs) or indirectly (eg. characteristics of users versus non-users). Any articles examining adoption from the health professional perspective (therapists, doctors, nurses) or PHR developers or researchers (eg. lessons learned, implementation issues) were excluded. Only *online* tools or applications that conformed to our definition of a PHR were included (see Appendix 1.3); if "PHRs" were paper-based, they were not considered in the synthesis.

APPENDIX 1: LITERATURE SEARCH STRATEGY

Table 1.1: Terms and Concepts related to PHRs

Broader Concepts	*Specific Terms/Synonyms*	*Related Terms*
Information and communication technologies (ICT) Health information technology (HIT) Consumer health information technology (CHIT) E-Health Telehealth / telemedicine Health information exchange (HIE)	Personal health record (PHR) Electronic personal health record Personal electronic health record Personal medical record Electronic patient record (EPR) Patient health record (PHR) Patient web portal Web portal / Web-based portal Internet portal / Internet-based portal Integrated personal health record Personally controlled health record (PCHR) Patient accessible electronic health record (PAEHR) Shared electronic record / Shared electronic patient record	Electronic health record (EHR) Electronic medical record (EMR) Computerized medical record Computerized patient record Electronic patient record system Clinical information systems Electronic health information network (EHI) Summary care record (SCR)

APPENDIX 1: LITERATURE SEARCH STRATEGY

Appendix 1.2: Revised Search Strategy for Electronic Databases (June 2010)

1. Health Records, Personal/[→ In CINAHL: Medical Records, Personal/]
2. "personal health record$".mp.
3. PHR$.mp.
4. (patient or personal or consumer).mp.
5. (electronic or online or internet or computer).mp.
6. (record or portal).mp.
7. Health/ or health.mp.
8. 4 and 5 and 6 and 7
9. 1 or 2 or 3 or 8
10. (attitude$ or perception$ or opinion$ or perspective$ or view$ or value or interest$).mp.
11. (barrier$ or facilitator$).mp.
12. 10 or 11
13. 9 or 12
14. Adoption/ or adoption.mp.
15. implementation.mp.
16. enrol$.mp.
17. acceptance.mp.
18. (behavior$ or behaviour$).mp
19. 14 or 15 or 16 or 17 or 18
20. 13 and 19
21. limit 20 to (English language and humans and yr="2000-Current")

[mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]

APPENDIX 1: LITERATURE SEARCH STRATEGY

Appendix 1.3: Criteria for considering studies for literature review

Types of participants

Study participants were patients or consumers with real or hypothetical access (either offered by researchers, health care provider, organization or initiated by patient) to an electronic personal health record (PHR). There are no exclusions with regards to health status of patient. There were no restrictions on age, location, gender or ethnicity. In the case where the "patient" was a child, we included the parents as the "users" of PHRs.

Types of interventions/PHRs

In line with the Markle Foundation's (2006) definition, a personal health record (PHR) was considered to be *any* type of online or web-based tool or application that allowed the patient or consumer to access, exchange or manage their own personal health information. All types of personal health records (PHRs) were included, including standalone models, tethered PHRs or patient portals, and integrated PHRs. PHRs offered on USB/flash drive or CDs/DVD formats and paper-based PHRs were excluded.

The following interventions were considered:

- Access to a standalone or self-contained electronic personal health record - that is, not linked with any health care institution, provider or insurer
- Patient access to personal health information through an electronic health record (EHR) or electronic medical record (EMR) of a health care provider/institution, regardless of whether patient has ability to edit information
- Access to a web-based patient portal to an EHR or EMR
- Access to online or electronic tools enabling email communication with a health care provider, as long as it was in conjunction with access to an electronic health record
- Assessment of perception, attitudes of patients towards PHRs, regardless of actual access

The following interventions were excluded:

- Access or provision of decision support, disease management, monitoring or electronic prescribing tools offered independently of a PHR (ie. not linked to PHR)
- Access to online or electronic tools enabling email communication or messaging with health care provided offered independently of a PHR (ie. not linked to PHR)
- EMRs or EHRs not directly accessible by patient (ie. can only be seen via healthcare provider)

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CONSENT FORM

Title of Project:	Adoption of electronic personal health records in young adults
Principal Investigator:	Gillian Bartlett, Associate Professor, Department of Family Medicine, McGill University
Institution:	McGill University
Project sponsored by:	Canadian Institutes of Health Research (CIHR) Catalyst Grant

INTRODUCTION

We are a team of researchers at McGill University working in cooperation with researchers from McMaster University, the Université de Montréal, Université du Québec a Montréal (UQAM), the University of Toronto, Radboud University Nijmegen (Netherlands), the Public Health Agency of Canada and Canadian Pharmacists Association. We are interested in how health information technology can be used to improve health care for patients.

The personal health record (PHR) is an emerging trend in health care that has received considerable interest and investment in recent years. Patients are increasingly demanding better quality of care and access to personal health information, and are using the Internet to seek out health information. PHRs are electronic tools that allow people to access, manage and share their health information online. They are initiated and maintained by the patient (and not the healthcare provider). Though many options exist, adoption rates for PHRs remain low, and little research has been done to date. There is a gap in our understanding as to why people are choosing to use (or not use) PHRs. The purpose of this study is to explore and understand the perception of PHRs and attitudes and issues underlying adoption in young adults.

We are asking for your participation in this research project. If you have any questions about the study or the consent form, you should feel free to ask at any time.

STUDY PROCEDURES

If you agree to participate, you will be asked to take part in a focus group, held at the Department of Family Medicine at McGill University (515 avenue des Pins Ouest) in Montreal, Quebec. The focus group will consist of 6-12 individuals. After a brief introduction, you will be asked a set of questions by the facilitator and asked to discuss it as a group. These questions will try to explore and understand your opinions and attitudes towards personal health records. Each focus group is expected last 1-2 hours, and refreshments will be provided. Focus groups will be tape-recorded and transcribed for analysis.

Before the beginning of the focus group, you will be asked to fill out a brief questionnaire, which should take no longer than 5-10 minutes. The questionnaires will be completely anonymous, and all information will be kept confidential. There may be additional one-to-one interviews, expected to last 1-1.5 hours, so if you are also interested in participating in these interviews, please leave your contact information at the end of the form.

WHAT ARE THE POSSIBLE RISKS?

There is minimal risk involved in participating in this study. Though we will emphasize the importance of maintaining confidentiality to all focus group participants, there is the potential risk that other participants will speak about the confidential discussions after the focus group.

WHAT ARE THE POSSIBLE BENEFITS?

You will receive no direct benefit from your participation in this study. We hope, however, that the results we obtain will help us develop a useful and relevant health tool that eventually, could benefit society as a whole.

WITHDRAWAL FROM STUDY AND PARTICIPANT RIGHTS

Your participation is completely free and voluntary. You will in no way be affected if you decide not to participate. You are free to withdraw from the study at any time, at no penalty or consequence to you whatsoever. You have the right to ask questions at any time.

WILL THERE BE ANY COSTS OR COMPENSATION?

Your participation in this research project will not involve any costs to you outside of the time required to participate. There will be a lottery draw for a gift certificate ($50) for each focus group.

CONFIDENTIALITY

All of the information obtained about you will be treated confidentially. On the interview transcripts, you will only be identified by a code. Only the Principal Investigator, Dr. Gillian Bartlett, and the research coordinator will have access to the study code key that identifies you. The study file will be kept at the McGill Department of Family Medicine. The study data will be kept for five years after the end of the research project for quality assurance. Results of this study may be published or communicated in other ways, but it will be impossible to identify you. For the purposes of ensuring the ethical conduct of the study, the Institutional Review Board may access the study data.

COMMUNICATION OF RESULTS

You can communicate with the research coordinator to obtain information on the general progress or the results of the research project. At the end of the project, there will be a written report/summary available, so if you leave your contact information, we will notify you when we have the details. However, we will not communicate any individual results to you.

IF I HAVE ANY QUESTIONS OR CONCERNS, WHO CAN I CALL?

If you have any questions about the research project now or later, you can contact:
Quynh Nguyen (Research Coordinator, MSc Candidate)
Department of Family Medicine, McGill University
Tel: (514)398-2437
Email: quynh.nguyen@mcgill.ca

Gillian Bartlett, PhD (Principal Investigator, Associate Professor)
Department of Family Medicine, McGill University
Tel: (514) 398-7375 x04587
Email: gillian.bartlett@mcgill.ca

If you have any questions regarding your rights as a research participant, you may contact:
Ilde Lepore, Senior Ethics Administrator
McGill University Institutional Review Board
Tel: (514) 398-8302
Email: ilde.lepore@mcgill.ca

SIGNATURE

The study has been explained to me and my questions have been answered to my satisfaction. Upon reflection, I agree to participate in this research project.

Participant name: _____

Signature: _____

Person who obtained consent: _____

Date: _____

☐ Yes, I agree to be re-contacted in the future for a one-to-one interview.
Contact information: _____

The research project was approved by the Institutional Review Board of McGill University on August 31, 2010.

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PHR STUDY: QUESTIONNAIRE

This questionnaire consists of 26 questions and should take about 5 minutes to complete. Your answers are completely anonymous and voluntary, and all information will be kept confidential.

1. What is your age?
   - ☐ 18-20
   - ☐ 21-24
   - ☐ 25-30
   - ☐ 30-34

2. What is your sex?
   - ☐ Male
   - ☐ Female

3. What is the highest level of education that you have completed?
   - ☐ High school
   - ☐ College
   - ☐ Undergraduate
   - ☐ Master's
   - ☐ Doctoral

4. What field are you currently studying?
   - ☐ Health/medical sciences
   - ☐ Other: _____

5. What is your province or region of permanent residence?
   - ☐ Quebec
   - ☐ Ontario
   - ☐ Manitoba
   - ☐ Saskatchewan
   - ☐ Alberta
   - ☐ British Columbia
   - ☐ New Brunswick
   - ☐ Nova Scotia
   - ☐ PEI
   - ☐ Yukon/Northwest Territories/Nunavut

6. What is your ethnic background?
   - ☐ White
   - ☐ Black
   - ☐ Asian
   - ☐ Latin American
   - ☐ Middle Eastern
   - ☐ Aboriginal
   - ☐ Other (please specify): _____

7. What language do you speak most often at home?
   - ☐ English
   - ☐ French
   - ☐ Other (please specify): _____

INTERNET USE

8. During the *past 12 months*, where did you primarily use the Internet for personal non-business use?
   - ☐ From home
   - ☐ From work
   - ☐ As a student from school
   - ☐ Other (please specify): _____

9. How often do you use the Internet at home in *a typical month*?
   - ☐ At least once a day
   - ☐ At least once a week (but not every day)
   - ☐ At least once a month (but not every week)
   - ☐ Less than once a month

10. In *a typical week*, on average, how many hours do you spend on the Internet, at home?
   - ☐ Less than 5 hours
   - ☐ Between 5 and 9 hours
   - ☐ Between 10 and 19 hours
   - ☐ Between 20 and 29 hours
   - ☐ 40 hours or more per week

11. During *the past 12 months*, have you used the Internet for any of the following activities?
    Please check all that apply:
   - ☐ Email
   - ☐ Electronic banking
   - ☐ Buying goods and services
   - ☐ Looking for medical/health information
   - ☐ Formal education/training
   - ☐ Government information
   - ☐ General browsing
   - ☐ Playing games
   - ☐ Chatting
   - ☐ Downloading music
   - ☐ Listening to the radio
   - ☐ Finding sports related information
   - ☐ Financial information
   - ☐ Reading the news
   - ☐ Travel information or arrangements
   - ☐ Looking for a job
   - ☐ Other (please specify): _____

12. During *the past 12 months*, have you used the Internet to search for medical or health related information?
   - ☐ Yes
   - ☐ No

13. During *the past 12 months*, what kind of medical or health related information did you search for using the Internet? Please mark all that apply.
    - ☐ Lifestyle (e.g., diet, nutrition, exercise, health promotion, illness prevention)
    - ☐ Alternative therapy (e.g., naturopathy, aromatherapy, acupuncture)
    - ☐ Health care system or delivery (e.g., structure, physicians)
    - ☐ Drugs or medications (e.g., aspirin, corticosteroids, viagra)
    - ☐ Surgeries (e.g., hernia, appendectomy)
    - ☐ Specific diseases (e.g., diagnosis, new research, treatment)
    - ☐ Analysis for specific symptoms (e.g., rash, fatigue, mole)
    - ☐ Other (please specify):
    - ☐ I did not use the Internet to search for medical or health related information

14. During *the past 12 months*, have you used the Internet to obtain the following from your family doctor or health care professional?
    - ☐ Appointments
    - ☐ Prescription renewals
    - ☐ Advice
    - ☐ Other
    - ☐ No / I have not used the Internet to obtain anything from my family doctor or health care professional

HEALTH

15. In general, would you say your health is:
    - ☐ Excellent
    - ☐ Very good
    - ☐ Good
    - ☐ Fair
    - ☐ Poor

16. In general, would you say your mental health is:
    - ☐ Excellent
    - ☐ Very good
    - ☐ Good
    - ☐ Fair
    - ☐ Poor

17. Do you have a regular medical doctor?
    - ☐ Yes
    - ☐ No

18. If 'Yes', is your regular medical doctor here in Montreal?
    - ☐ Yes
    - ☐ No
    - ☐ I do not have a regular medical doctor

19. Do you have one or more chronic health conditions (ie. long term conditions diagnosed by a health professional, such as asthma, diabetes, heart disease, chronic bronchitis, mood disorders, etc) ?
    - ☐ Yes
    - ☐ No

20. Do you keep any paper copies of your medical records?
    - ☐ Yes
    - ☐ No

21. Do you keep any electronic copies of your medical records?
    - ☐ Yes
    - ☐ No

22. Had you previously heard of an electronic personal health record?
    - ☐ Yes
    - ☐ No

23. Have you ever used an electronic personal health record?
    - ☐ Yes
    - ☐ No

24. Do you think an electronic personal health record could be useful in helping you manage your health?
    - ☐ Extremely useful
    - ☐ Very useful
    - ☐ Somewhat useful
    - ☐ Not very useful
    - ☐ Not at all useful
    - ☐ Don't know

25. In general, how concerned (are you/would you be) about privacy on the Internet? For example, people finding out what websites you have visited, others reading your e-mail?
    - ☐ Not at all concerned
    - ☐ A little concerned
    - ☐ Somewhat concerned
    - ☐ Very concerned
    - ☐ Extremely concerned

26. How concerned (are you/would you be) about the privacy and/or security of putting your personal health information on the Internet?
    - ☐ Not at all concerned
    - ☐ A little concerned
    - ☐ Somewhat concerned
    - ☐ Very concerned
    - ☐ Extremely concerned

MSc Thesis Project:

Adoption of electronic personal health records (PHRs) in young adults

Quynh Nguyen
Dept. of Family Medicine, McGill University

Overview

- Focus group
- What is a PHR?
- Types of PHRs
- PHR Features
- Examples

PHR Focus Group

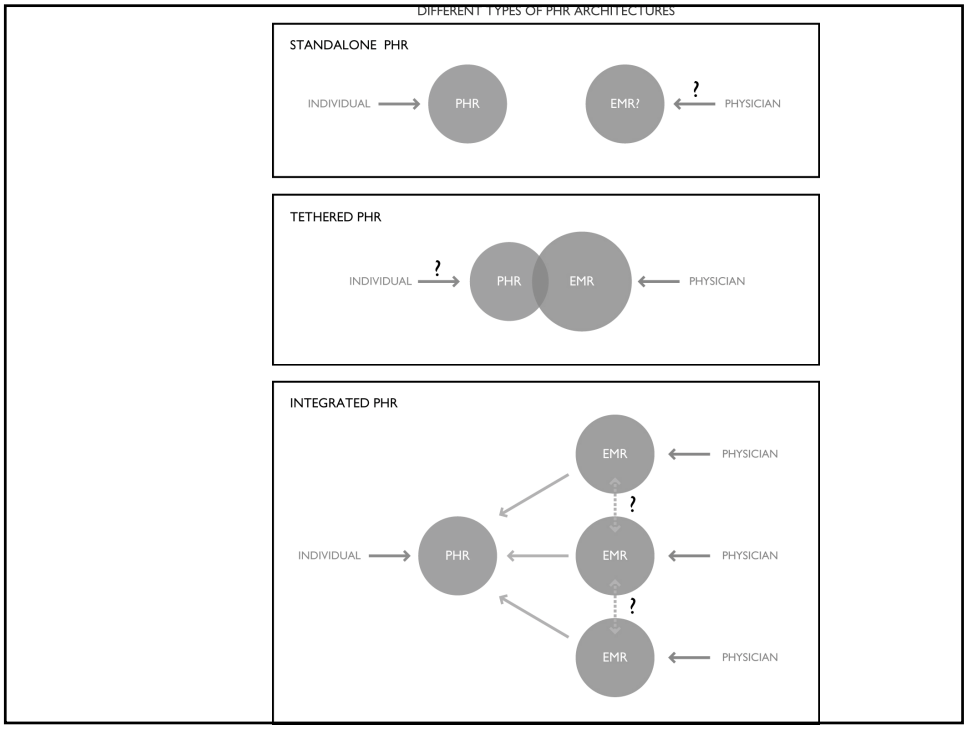
- Goal of focus group
- Recording and confidentiality
- Guidelines for focus group

What is a PHR?

- Personal health record (PHR):
  - Online/electronic tool that allows individuals to access, manage, and share their health information
  - Initiated and maintained by patient/individual
- Different from an EMR/EHR (healthcare provider)
- Public and private, free/fee

Types of PHRs

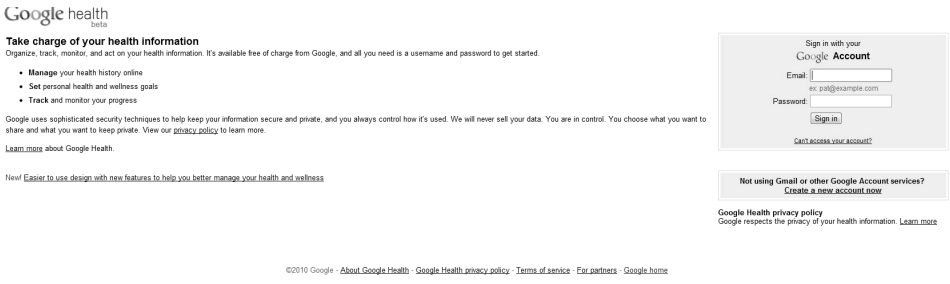
- Standalone
  - Does not connect with other systems
  - Patient enters/updates info
- Tethered
  - Institution-specific, "patient portals"
- Integrated
  - Data comes from variety of sources (providers, EMRs)
  - Communication between patients and providers



PHR Features

- Basic:
  - Medical history
  - Allergies, medications
  - Vaccinations
  - Emergency contact, insurance
- More advanced:
  - Scheduling appointments
  - Rx renewal, drug interactions
  - Secure patient-physician email
  - Request lab and other test results
  - Patient education resources

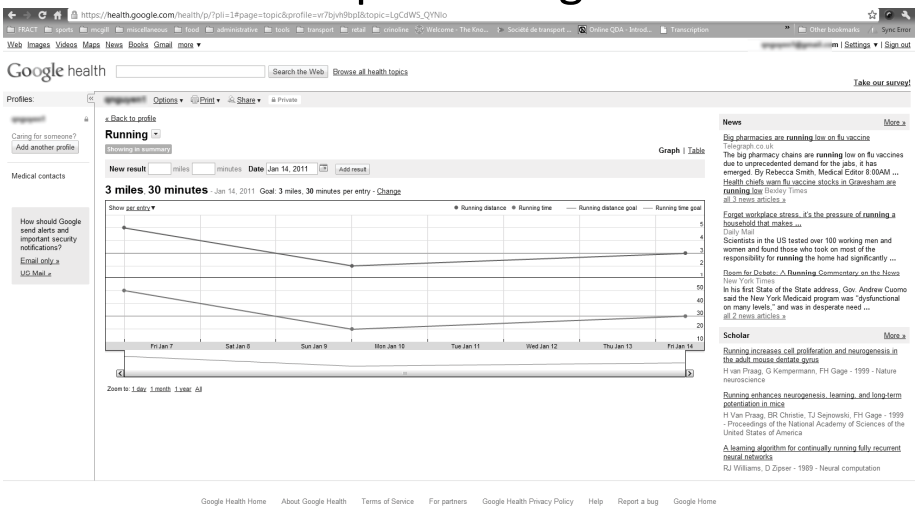
PHR Examples: Google Health



Google Health, www.google.com/health

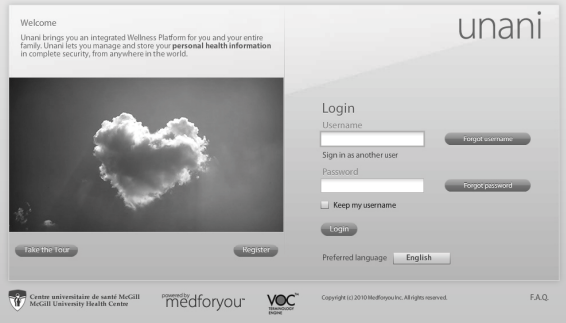
APPENDIX 4: PHR INTRODUCTORY PRESENTATION

PHR Examples: Google Health



Google Health, www.google.com/health

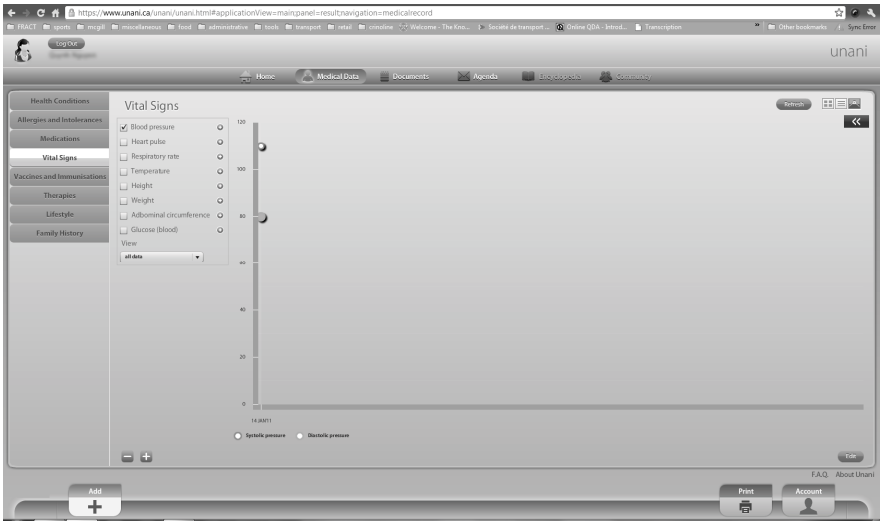
PHR Examples: UNANI



MUHC & MedforYou's UNANI, www.unani.ca

APPENDIX 4: PHR INTRODUCTORY PRESENTATION

PHR Examples: UNANI



APPENDIX 5: INTERVIEW GUIDE

Focus Group Topic Guide (Preliminary Version)

Distribute consent forms and questionnaires. Collect signed/completed consent forms and questionnaire before beginning focus group

Introduction (5 minutes)

Facilitator will introduce her/himself (and the assistant), and will briefly go over the following points in their own words:

1) *Goal of the focus group*: To explore their understanding and awareness of an electronic personal health record (PHR) and establish what factors are important in their decision to adopt (or not adopt) a PHR.
2) *Recording and confidentiality*: This discussion will be recorded and transcribed for analysis, but all names will be replaced by codes and no names will appear on any subsequent transcripts or documents. Assistants are present to take notes, but no names (only codes) will be documented.
3) *Guidelines for focus group*: The role of the facilitator will be to guide the discussion, but participants are free (and encouraged) to talk not only to the facilitator, but to other participants directly. The aim is really to explore the ideas and opinions of the participants.

Introducing personal health records (5 minutes)

A quick 5-minute presentation from the focus group facilitator to introduce the topic of personal health records to the group.

Prompts for general discussion (30-45 minutes)

Opening question:

- *So, to start off, why don't we go around the table – everyone can introduce themselves quickly, then tell us what did you know or think about PHRs before coming here today?*
- *What do you see as being potential benefits or advantages to using a PHR?*
- *What might be some drawbacks or concerns with using a PHR?*
- *What might make you want to use a PHR?*
- *What might prevent you from using a PHR?*
- *What features or characteristics would you want your PHR to have?*
- *Do you think that a PHR would be useful to you, and how would you see yourself using one?*

Conclusion/Debrief (5-10 minutes)

- Summary*: Does this correctly describe what was said?*

To be addressed to each participant:

- *Is there anything else you would like to add or clarify?*
- *This is the first in a series of groups that we are doing. Do you have any advice for how we can improve?*

To the group:

- *Are there are any other questions that you have about the study? Thank you all for your participation in this study!*

APPENDIX 6: ADDITIONAL QUESTIONNAIRE RESPONSES

Table 7.1: Frequency of Responses from Pre-Interview Questionnaire: Internet use, health, and privacy concerns (n=29)

Participant Characteristics	n (%)
Frequency of Internet use per month	
Atleast once a day	26 (89.7)
Atleast once a week, but not every day	1 (3.4)
Less than once a month	2 (6.9)
Frequency of Internet use per week from home	
<5 hours	5 (17.2)
5-9 hours	4 (13.8)
10-19 hours	7 (24.1)
20-29 hours	7 (24.1)
30+ hours	6 (20.7)
Used Internet to search for medical or health related information	22 (75.9)
Self perceived health*	
Excellent	6 (20.7)
Very good	13 (44.8)
Good	8 (27.6)
Fair	1 (3.4)
Poor	0
Access to regular care*	
Regular physician in Montreal	9 (31.0)
Regular physician outside of Montreal	9 (31.0)
No regular physician	10 (34.5)
Chronic health conditions*	5 (17.2)
Kept paper health records**	13 (44.8)
Kept electronic records of health**	3 (10.3)
Heard of a PHR**	9 (31.0)
Used a PHR**	2 (6.9)

APPENDIX 6: ADDITIONAL QUESTIONNAIRE RESPONSES

Table 7.1: Frequency of Responses from Pre-Interview Questionnaire (continued)

Participant Characteristics	n (%)
Perceived usefulness of PHR in managing health**	
Extremely useful	5 (17.2)
Very useful	10 (34.5)
Somewhat useful	9 (31.0)
Not very useful	0
Not at all useful	0
Don't know	3 (10.3)
Privacy concerns (general)**	
Not at all concerned	2 (6.9)
A little concerned	5 (17.2)
Somewhat concerned	9 (31.0)
Very concerned	8 (27.6)
Extremely concerned	3 (10.3)
Concerns about privacy/security of health information on the Internet**	
Not at all concerned	4 (13.8)
A little concerned	6 (20.7)
Somewhat concerned	3 (10.3)
Very concerned	10 (34.5)
Extremely concerned	4 (13.8)

*missing response=1
**missing responses=2

APPENDIX 7: LIST OF THEMES AND SUBTHEMES

VIEWS ABOUT ONLINE PERSONAL HEALTH RECORDS
Theme 1A: Perceived Advantages of a Personal Health Record ▪ A comprehensive, consolidated record ▪ Accurate record of medical information ▪ Accessibility of health information ▪ Integrated health record ▪ Improving efficiency of healthcare system ▪ Research and identifying population trends
Theme 1B: Potential PHR Users ▪ Age and computer literacy ▪ Health status and the "worried well" ▪ Caregivers
Theme 1C: Concerns with Using a PHR ▪ Misuse of information by employers and insurance companies ▪ Stigma and discrimination ▪ Use of information for advertising or profit ▪ Data integrity and complexity ▪ The health professional perspective
EXPECTATIONS FROM USING AN ONLINE PHR
Theme 2A: Characteristic of an Ideal PHR ▪ Usability ▪ Customizability and control over what is shared ▪ Cost
Theme 2B: Use of PHR for Preventative Health and Lifestyle ▪ Tracking health and recognizing patterns ▪ Comparing to the norm ▪ Understanding hereditary influences
Theme 2B: Taking More Control of Their Health ▪ Increased independence and autonomy ▪ Avoiding care through self-diagnosis ▪ Reputable health information
Theme 2D: Making the PHR Worthwhile ▪ Making it worth the time ▪ Providing interactivity and reward