ORIGINAL ARTICLE

Family attitudes towards an electronic personal health record in a long term care facility

PMD Nippak *[1], WW Isaac[1], A Geertsen[1,2], CJ Ikeda-Douglas[1]

[1] *Ryerson University, Toronto, Canada*
[2] *Baycrest Centre for Geriatric Care, Toronto, Canada*

Received: August 6, 2014 **Accepted:** March 10, 2015 **Online Published:** March 23, 2015
DOI: 10.5430/jha.v4n3p9 **URL:** http://dx.doi.org/10.5430/jha.v4n3p9

ABSTRACT

Objective: To explore the perceptions of family members regarding the importance of an electronic personal health record (EPHR) called MyChart as a healthcare information source to support the care of their loved ones within a long term care (LTC) facility in Toronto, Ontario.
Methods: One hundred and fifty eight family members of the patients in six LTC units at the hospital were given a survey to determine their perceptions regarding the utility of the content items within an EPHR that was recently adopted by the LTC institution.
Results: The response rate was 41% (n = 65). Many family members (n = 48) felt it was important to have access to their loved one's EPHR. Respondents ranked test results (38%; n = 25), doctor's clinical notes (26%; n = 17), medication lists (15%; n = 10) and upcoming appointments (11%; n = 7) as the number one most important content item that they would want to have access to. In addition to the standard content items found within an EPHR, family members requested electronic access to a variety of additional medical content items that are not currently offered within the EPHR, such as status alerts. Overall, they felt that an EPHR would enhance communication between the care team and the family, however 30% of family members identified concerns linked to security and confidentiality of the electronic health record information.
Conclusions: Family members felt that an EPHR would be an important tool in the LTC facility to assist with information exchange between care providers and the family. It is important to consider that the additional information requested beyond what is traditionally found in an EPHR as well as the specific communication concerns raised, may be limited to a LTC setting.

Key Words: Electronic health records, Healthcare management, Personal electronic health records, Technology

1. INTRODUCTION

Since 2001, Canada has committed to developing and implementing electronic health records (EHRs) across the country to facilitate the exchange of healthcare information with the ultimate goal of producing a more efficient, cost effective and safer health care system.[1–9] The focus to date has been largely on the development of EHR systems within individual organizations, however the long-term goal is to provide the necessary linkages and networks that would allow for the sharing of health data among health professionals across a region and one day, the country.

Since an EHR remains focused on the exchange of healthcare information between healthcare professionals, alternative platforms that include the patient in the exchange of healthcare information, often referred to as an electronic personal

*Correspondence: PMD Nippak; Email: pnippak@ryerson.ca; Address: Health Services Management, Ryerson University, Toronto, M3B 2K5, Canada.

health record (EPHR), have been suggested. An EPHR incorporates the patient into the exchange of healthcare information through the utilization of specific web-based platforms and is believed to enhance the participation of the patient in their own health care,[10–13] while still enabling healthcare providers to share this information amongst themselves to further enhance the continuum of care.[2, 14] The National Alliance for Health Information Technology (NAHIT), has identified an EPHR as "an electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared and controlled by the individual".[15] The potential benefits associated with an EPHR are large given that in the past patients only had access to their medical records by visiting the medical records department of a hospital or health care institution to request them, and often it took several months to obtain a copy of the record.

Despite the many benefits and growing international utilization of an EHR these types of initiatives remain in their infancy in Canada.[2, 16] In Ontario, one urban hospital has adopted its own EPHR record called MyChart in 2010. MyChart is a secure and private web-based platform that offers self-management tools that are entirely accessed and controlled by patients such as diaries to record their health history, symptoms, and medications, emergency contact information as well it provides access to health education sites and appointment scheduling features.[17]

In a unique attempt to facilitate the exchange of an EPHR between different care settings this urban hospital approached our centrally located long-term care facility to implement MyChart. In preparation for a successful implementation a variety of stakeholders were surveyed in addition to patient user groups to ensure that the MyChart EPHR when launched would optimally serve them. Given that the 472 bed long term care (LTC) facility provides care to many residents with cognitive impairment, family members were identified as important participants in the delivery of care to many residents.

Based on this the objective of the current study was to survey these family members of patients within the LTC facility to examine their perceptions surrounding the importance of an EPHR as a communication tool and to identify the informational priorities and concerns of families regarding MyChart to enable them to effectively tailor the technology if necessary to meet the needs of family members overseeing the care of their loved ones.

2. METHODS

The study was completed at an urban facility recognized as an academic health sciences Centre for Geriatrics. The facility offers out-patient wellness programs, outpatient clinics, and has both a LTC facility with 472 beds as well as a 300-bed continuing care hospital.

2.1 Design

The current study utilized a cross sectional approach to capture the perceptions of family members of patients, within the long-term care facility, surrounding the utility of having access to an EPHR to enable them to manage their loved ones care.

2.2 Sample

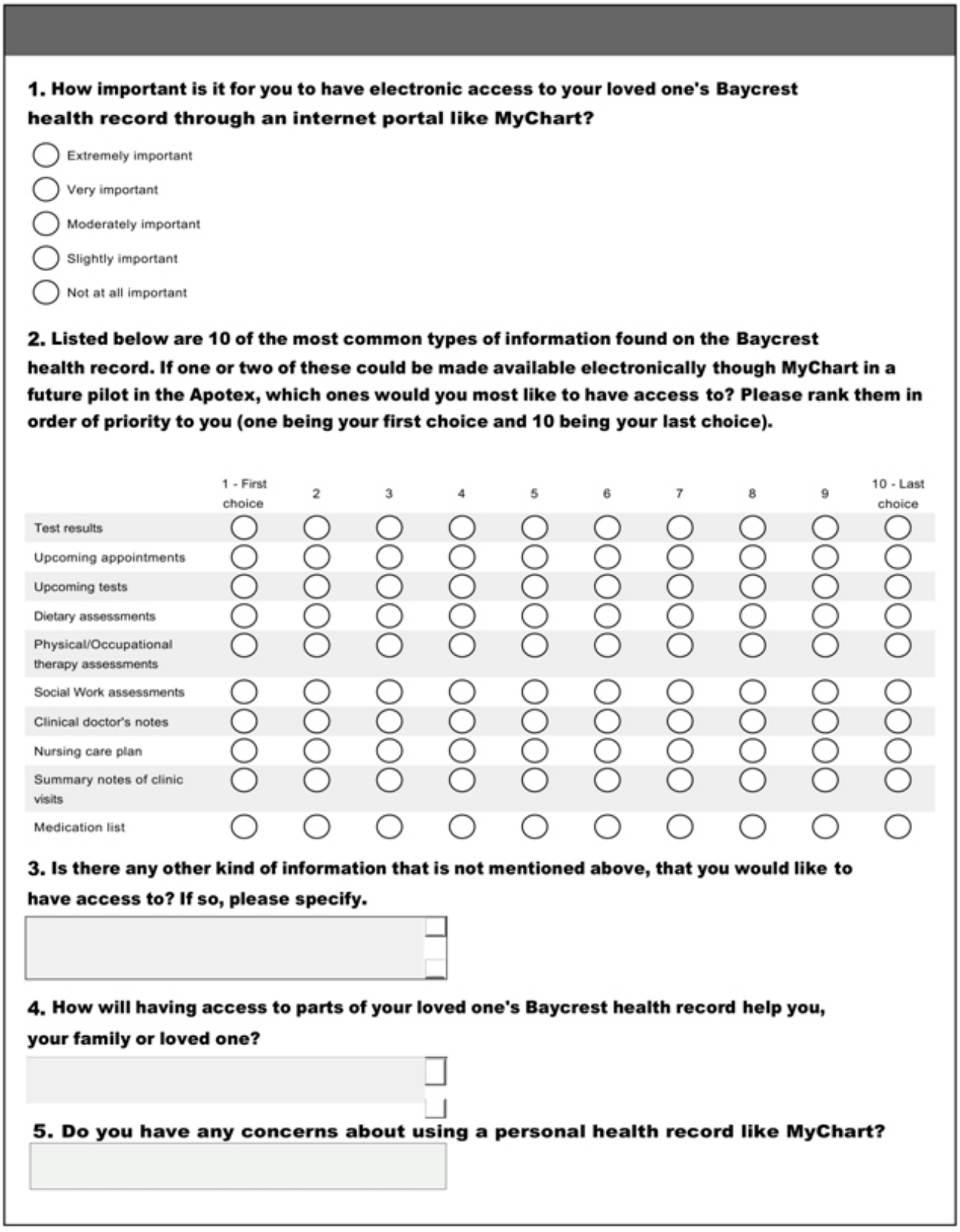
The target population for this study were family members of the residents residing in all six units in the LTC facility. A convenience sample of 158 family members, which represented all family members that had provided contact information to the institution, where surveyed. The study received ethics approval.

2.3 Instrument/Tool

The survey was comprised of five questions, which were created for distribution through SurveyMonkey©. The first two questions were rating scale questions regarding the importance of having EPHR access and the utility of the items contained within the EPHR and the remaining three questions were open-ended questions to encourage family members to offer any suggestions or comments related to the topic of an EPHR (see Figure 1). Based on the site recommendations, no demographic information was collected about the patients or the family members that completed the survey. The questionnaire was reviewed by the Manager of Informatics, e Health at the hospital and their team to ensure that it met their privacy standards and accurately reflected the elements found in the EPHR.

2.4 Procedure

Following ethics approval from the hospital, a link to the SurveyMonkey© questionnaire along with an introduction letter and instructions for completion were sent to the secretary of the Director of Care who then proceeded to forward it to all six unit directors who forwarded the information to all family members with current email addresses within their contact information. The survey was subsequently distributed to a total of 158 families. The study was closed after 16 days. One week following the release of the survey, participants were sent a reminder to strengthen the response rate. A final reminder was sent out two days prior to the close of the survey.



1. How important is it for you to have electronic access to your loved one's Baycrest health record through an internet portal like MyChart?

- ◯ Extremely important
- ◯ Very important
- ◯ Moderately important
- ◯ Slightly important
- ◯ Not at all important

2. Listed below are 10 of the most common types of information found on the Baycrest health record. If one or two of these could be made available electronically though MyChart in a future pilot in the Apotex, which ones would you most like to have access to? Please rank them in order of priority to you (one being your first choice and 10 being your last choice).

	1 - First choice	2	3	4	5	6	7	8	9	10 - Last choice
Test results	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
Upcoming appointments	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
Upcoming tests	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
Dietary assessments	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
Physical/Occupational therapy assessments	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
Social Work assessments	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
Clinical doctor's notes	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
Nursing care plan	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
Summary notes of clinic visits	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
Medication list	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯

3. Is there any other kind of information that is not mentioned above, that you would like to have access to? If so, please specify.

4. How will having access to parts of your loved one's Baycrest health record help you, your family or loved one?

5. Do you have any concerns about using a personal health record like MyChart?

Figure 1. Survey tool

2.5 Analysis

Descriptive statistics were used to analyze the data. Any comments and/or suggestions provided by study participants in the survey were analyzed for thematic content. The open ended data items were coded according to emerging categories based on a review of the total responses both within and across the participants for each question.[18, 19] The open ended data analysis framework utilized a grounded theory approach. Using one large sheet of paper, all of the excerpts sharing the same code were noted along with each corresponding identifier.[19] In the next step axial coding was applied to examine whether there was a relationship between the various categories to determine whether any category could be collapsed into a broader theme.[19] This process was performed by two independent researchers and there was an 88% agreement obtained with respect to the categories chosen for each of the participant response's across the three open-ended questions.

3. Results

The final response rate was 41% (n = 65). The desire to have electronic access to their loved one's EHR was significant, with 74% of respondents stating that having EPHR access was very important (n = 38) or extremely important to them (n = 10).

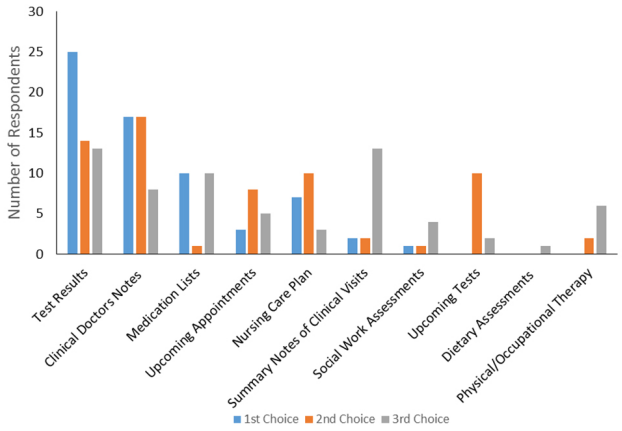


Figure 2. Top 3 ranked MyChart items

When asked to rank order the key information elements that they would like to see within the EPHR, 38% (n = 25) of family members indicated their number one choice as patient test results. Other elements in the chart that ranked as the top choice for family members were clinical doctor's notes by 26.1% (n = 17) of family members, medication lists (15%; n = 10), and upcoming appointments (5%; n = 3). Although, only 11% (n = 7) of family members selected nurses notes as their first choice, almost 20% (n = 13) of respondents had it listed as either their second or third most important access item. Finally, 3% (n = 2) of respondents ranked summary notes of clinical visits as their top ranked choice. For second ranked choice selections, the most selected item was clinical doctors (n = 17), while test results were the second (n = 14) and both the nursing care plan (n = 10) and upcoming tests (n = 10) were together selected as the second ranked item by participants. Finally, the top chosen third rank items were test results (n = 13) and summary notes of clinical visits (n = 13) (see Figure 2).

As shown in Figure 2, the top three pieces of information that are felt to be the most necessary on an EPHR are test results, doctors' notes and medication lists.

The first open ended question (Question 3) asked family members if they could suggest any additional information, beyond what is currently found in the MyChart EPHR, that they would like to have available to them to assist with their loved ones care. Three themes emerged; reporting features (types and elements), status alerts to changes, and staff issues. Of the 31 respondents that provided open-ended feedback, 55% of them requested access to specific reporting features. For example, several family members identified feature elements, such as "access to blood work" and another indicated "access to personal hygiene, another person indicated "access to social interaction, behavior and mood". In contrast some family members identified feature types, "Test results, medication lists, doctor's notes, nursing care plan, upcoming tests are all very important to know-so selecting only a few is not an accurate way to measure what is more important than the other options". As well, a minority of respondents (6%, n = 2) felt they would like access to psychiatric reports or assessments. Within the second theme, 10 (35%) of family members indicated that they would like some kind of "status alert to changes" in their family member's health status. The responses included status alert around accidents, changes in behaviour, mood, or physical status and level of participation in daily activities as they change. For example, one family member stated they wanted to know of "any noticeable changes in my family member - be it medical/social/abilities/temperament, *etc*. Clues that my loved one is deteriorating in some capacity". Another family member provided the directive "notify the family of any changes when they occur - health, medication, behavior". Finally, the last theme emerged related to the staff (n = 4), as two family members suggested having access to physician contact information or the ability to request a change in physician. For example, one family member stated they wanted access to "admin/health provider names and contacts". One family member indicated that they "would like to be able to have their mother choose to see a different physician than the one assigned to her ward (see Table 1).

Table 1. Access to information

Comments	**Alerts to changes in status**	**Reporting features (elements and type)**	**Staff (concerns, contacts or issues)**	**None**
Example Attributes	***"Changes in behaviour, health, incidents or accidents that occur, progression/ deterioration in health status"***	***"all types of info are vital to me in order to have complete picture"***	***"issues of concern identified by staff"***	
We'd very much like to have the two monthly calendars, on-floor and off-floor, available to ensure our visits are appropriately timed.		1		
No				1
Accidents, Incidents, Changes - All	1			
Blood pressure readings monthly recorded weight incident notes report notes dining room seating changes and rationale therapeutic recreation assessment any other notes or comments or plans.		1		
Psychiatric assessments and treatment notes.		1		
The progression of her condition/deterioration and her comfort status.	1			
I believe ALL the above are necessary.		1		
Psychiatry consult notes		1		
I don't believe the doctors will make their true feelings available on line for patient families.			1	
list of events (problems) for the past week that occurred with the patient.	1			
Emotional status; issues or concerns of staff regarding loved one.	1		1	
no				1
Any and all urgent or important issues concerning care.	1			
Daily staff notes re changes in condition	1			
Significant changes to baseline physical or mental health status should be flagged and presented in a highly visible fashion.	1			
daily activity and assessment report		1		
notify the family of any changes when they occur - health, medication, behaviour.	1			
admin/ health provider names and contacts			1	
any noticeable changes in my family member - be it medical/ social/ abilities/temperament *etc.* Clues that my loved one is deteriorating in some capacity.	1			
Test results, medication lists, doctor's notes, nursing care plan, upcoming tests are all very important to know - so this is not an accurate way to measure what is more important than the other options.		1		
changes in behaviour	1			
I cannot rank order the list above because all of the types of information are vital to me as care manager.		1		
daily/ weekly/ monthly records of weight measurements, blood pressure/ O_2/ heart rate measurements; frequency of bowel movements, *etc...* it would be very helpful to have such recurring measurements put in a chart format in order to be able to see trends more easily.		1		
HER BLOOD WORK		1		
hygiene routine		1		
social interaction, behaviour, mood		1		
I would like to be able to have my mother choose to see a different physician than the only one assigned to her ward.			1	
I would want to be sure that the list of Blood Tests that I presented were taken monthly and included in the test results.		1		
Hard to prioritize as all areas above are crucial; the order will change depending on the personal functional status of the resident and if that resident has a private caregiver.		1		
daily nursing notes		1		
real time chart		1		
Total (n = 31)	10	16	4	2
% of population responding to question	34.5%	55.2%	13.8%	3

As shown in Table 1, the open ended responses to question three have been summarized to show the various responses to the types of information that might be accessible to caregivers.

The fourth question asked how having electronic access might be helpful to you, your family member or loved ones and 56 family members provided responses to this question. Five categories emerged: 1) improved efficiency in communication, 2) improved quality of communication, 3) enhanced data sharing, 4) facilitated monitoring of health and care, and 5) it would not be helpful. The majority of comments to this question fell within the improved quality of communication theme. Within this theme 36 responses were provided. One family member indicated that it would "help us to communicate with them". Another individual indicated "it would make me a helpful participant in my mother's care". Respondents described the communication as "providing control" and "being accurate" and enabling the caregiver to be an "active participant". Sixteen participants indicated that access to their loved one's EPHR would improve the efficiency of communication with staff. For example, one caregiver indicated that it will "allow for access at any time and therefore one is not dependent on the staff". Another individual stated that it would provide a "faster response to specific information and up-to-date accuracy without having to call and wait on the phone for someone to answer". Several respondents used terms such as "timely", "efficient", and "faster" to describe the communication benefits of an EPHR.

The responses given indicate how access to records will help the patients and/or their families.

Within the enhanced data sharing theme (n = 2) that emerged for question 4, the caregivers identified geographical barriers that could be overcome through the use of an EPHR. Within the fourth theme, facilitated monitoring of health and care, 15 individuals provided responses. In several responses the term "monitor" was used. For example, one participant indicated they would be "able to monitor the care and add or remember certain issues" while another individual indicated that it would make it "easier to manage and monitor care", finally another individual indicated that they are "constantly monitoring their loved ones condition and situation in order to provide the best possible care and a beautiful life". Finally, three caregivers (5%) indicated that they did not feel that an EPHR would be helpful, however they did not provide any reasons for why.

The final question (Question 5) asked if anyone had any concerns about having electronic access to their loved ones health record. Of the total number of 47 individuals that responded, 68% stated they had no concerns at all. The concerns that were expressed fell into three categories: 1) Security, confidentiality and Privacy (n = 14), 2) Knowledge and Understanding (n = 5), and 3) Staff (n = 4). For the first theme, seven individuals used the word "confidentiality", while five participants used the term "secure" and three participants used the term "privacy" to describe their concerns. One participant made an indirect reference to security issues through the statement that they were "concerned about hackers getting into the health records and compromising the information". Another participant stated indicated that they were "not quite sure that the confidentiality of on-line information is secure". Finally, one participant indicated that they "just want to be sure that it will be private and secure".

Within the Knowledge and Understanding theme the following statements were made by participants to reflect their concerns about using MyChart, "Not personally, but I do worry that some people may misinterpret information or get concerned about test results they don't understand" and "not understanding the information and fearing abnormal values" and "Personally, none, however I feel that some families would need to be educated in this area". The third theme related to Staff revealed participants (n = 4) concerns surrounding the impact of using MyChart on staff operations and their communication exchange with family (see Table 2). For example, one participant stated felt that it could create a "risk of downloading responsibility to family and eliminating opportunities to talk in person to the staff". Another participant indicated asked "Will staff have time to input the information?" Finally, one participant stated "I am concerned that staff might not buy into this. My experience is that this hospital does not have a culture of open communication with family".

As shown in Table 2 the greatest number of respondents had no concerns about personal health records.

4. Discussion

Few studies have examined how an EPHR might help family members acting as caregivers to patients within a LTC facility. However, family members are often assigned to monitor the care of an individual placed in LTC because they have legal access rights to health information as a result of a cognitive impairment within the patient or because the individual patient has provided permission. While family members may not be providing direct care anymore an EPHR may provide them with an opportunity to remain informed about their loved ones health. The overall findings indicated that family members felt that an EPHR was an important information tool to support their loved ones care and they ranked test results, clinical doctors notes and medication lists as the most important items that they would want to have access to.

Table 2. The concerns about using a personal health record

Comments	No Concerns	Security/ confidentiality/ privacy	Knowledge and Understanding	Staff	Outlier
Example Attributes	***"none"***	***"depends on secure access; as long as private & secure"***	***"worry that some may misinterpret info"***	***"concerned staff may alter data if publically accessible"***	
Absolutely not. I work in Health Care and would welcome more information about our father.	1				
None - I think the privacy issues concerning elderly patients are ridiculous - as the responsible adult for elderly parents we should be totally able to access any info no matter where (outside of facility as well).	1				
None, as long as other forms of communication of this information will still be available.	1				
I have no idea what a personal health record like MyChart is, so I am unable to comment on this.			1		
depends on secure access	1	1			
None	1				
No	1				
yes i do. how do you make sure the information is secure? bad idea to post this online.		1			
No Why?	1				
Of course there are concerns if for example the social security number, health card number or any personal identification data is on the internet. The other concern is that somehow the information could be used in such a way to harm the loved (or the family).	1	1			
No	1				
None	1				
None	1				
I hope it is a secure and confidential access, for the resident's family only.		1			
NO	1				
Will staff have time to input the information?				1	
I just want to be sure that it will private and secure.		1			
I assume that there will be precautions regarding patient privacy. so i have no concerns.	1	1			
no	1				
No concerns. Very important that this is introduced as soon as possible.	1				
no	1				
Not personally - but I do worry that some people may misinterpret information or get concerned about test results they don't understand.	1		1		
I am concerned that the staff might not buy into this. My experience is that the staff does not have a culture of open communication with family.				1	
No	1				
none	1				
No	1				
No	1				
no	1				
No	1				
I am not quite convinced that the confidentiality of on-line information is secure.		1			
Not understanding the information and fearing abnormal values. Concern the health providers notes would not be altered.			1	1	
I would like it.	1				
confidentiality / accuracy		1			
Personally, none, however I feel that some families would need to be educated in this area.	1		1		
no	1				
no	1				
concerned about hackers getting into health records and compromising the information		1			
privacy		1			
Keeping it confidential		1			
NO CONCERN	1				
maintenance of confidentiality risk of "downloading" responsibility to family and eliminating opportunities to "talk" in person to the staff.		1		1	
Not familiar with MyChart			1		
No	1				
I have no concerns as long it is kept under the guide lines of the "Confidentiality Act".	1	1			
only concern again is to ensure complete confidentiality.		1			
Got for it! And be mindful of the costs incurred.	1				1
no	1				
Total (n = 47)	32	14	5	4	1
% of population responding to question 5	68.1%	29.8%	10.6%	8.5%	2.1%

Similarly, other studies have reinforced the utility of an EPHR as a tool developed to help patients and their loved ones remain informed about strategies surrounding their care.[12,20,21,23–29] This was depicted in a 2005 survey of patient users of an EPHR in a family group practice where patients indicated that they found that having timely access to their test results and other information from their medical records made them feel like they were active participants in their own care.[21] Another study indicated that an EPHR helped patients get answers to simple questions quickly and enabled them to remember what a physician said at their last appointment.[22] Similar results have been reported from family members in an acute care setting, which was defined as those individuals given access to a parent's or loved ones' health record, a similar definition to that used within the current study. They found that family members felt that an EPHR had important functionality, which is consistent with other studies of patient individual's perceptions that an EPHR can improve the management of healthcare of the patient by family members of the patient.[21–23]

With regard to the kinds of information families would find most helpful, many of the findings within this study were consistent with those conducted with either the patient or the family members in other healthcare settings, such as acute care or outpatient services. Specifically, access to test results and doctor's notes topped the list as being the most desired items, which have been the same types of items selected within other studies where different care settings were examined.[21,22,30,31] This consistency across different types of samples and settings may indicate that some EPHR elements are significant independent of these variations.

Unique to this study was the ranking given by family members to the data element, nursing notes. Thirty one percent of participants' ranked nurse's notes as one of their top three important EPHR elements (11% placed it as their top choice). To date the literature has not singled out nursing care plans or notes as being an element that patients would typically desire access to.[23,25,32–34] However, the majority of studies to date examining the utility of an EPHR have been done in outpatient settings where there is often a complete absence of the type of nursing care plans required within acute and LTC environments. Unlike within an outpatient setting, within a LTC setting nurses assume a significant portion of the direct care requirements.[32] It is possible that this finding may be specific to LTC only and may be linked to the increased role that nurses and particularly nurse practitioners assume over the clinical care of patients,[33] however given the paucity of research it is difficult to discern. Consistent with the current study findings, Thede (2009) identified that caregivers require very specific consideration when the elements of an EPHR are being constructed and indicated that nurses should play a very significant role in any EPHR development.[34] They described that nurses assume several direct care responsibilities over patients and as a result they should be included in the decision making process surrounding the development of an EPHR developed for the patient.

Finally, it is also possible that in the current study nursing notes ranked high because the caregivers were surveyed, rather than the patient, which is often the stakeholders perspective examined in other studies.[23,25] For, in the majority of studies the patient's perspective is examined, which may explain why test results and doctors clinical notes are the most preferred access elements. Unlike patients, caregivers may not always be around to have direct exchange with nurses and as a result they may want to be able to review their notes to inform them about their loved ones health and care.

The item, medication lists, was ranked as a first choice by a small fraction of the family member's in the current study, which is inconsistent with other studies where it has been given a high ranking.[35] However it was selected as one of the top three ranked choices by 32% of individuals indicating that it does remain a concern to family members. The fact that it was not ranked as a top choice by many participants was an unexpected result given that complications from interactions with multiple medications have been reported in many seniors within acute care who suffer from multiple chronic conditions requiring medication management.[36,37] Thus, it is definitely a concern that has been identified within the literature, however it may not be a recognized concern of caregivers who were examined within the current study. Alternatively, the care setting may have influenced the findings regarding medication management and has been identified as a key factor in other studies.[36] For example, it is possible that these concerns may not be as prevalent in a LTC facility where the patient may reside within the facility for several years and not be subject to frequent medication changes, which has been identified as a key risk factor associated with medication errors.[38,39]

Given the variation that exists across the literature with regards to the access items available within an EPHR,[23,40] which have been shown to vary as a function of user type and healthcare setting, the reported rankings in the current study can be used to begin to establish a framework of priority items for the LTC facility. The selected items as well as the rank ordering could be used to inform decisions around what an optimal EPHR interface should look like within a LTC facility.[41] For very few healthcare facilities within Ontario have adopted an EPHR to date to guide or inform

what the key access items should be. Consistent with the Ontario Personal Health Information Act, which deems that individuals have the right to access their full health record, the facility determined that full EPHR access would support that mandate, with key consideration given to the ranking provided by the caregivers.

The findings regarding the rank ordering of the key access elements within the current study can assist with the tailoring of an interface in a way that is meaningful to the organization and the expressed interests of family members/caregivers within this particular facility. Screens that offer summary data or "health dashboards" that help family members monitor care and treatment and/or alert them to specific changes that have occurred and treatment plans that have been adjusted are recommended for adoption within this LTC facility based on the findings. Given the small sample size utilized within the current study it is difficult to discern whether these additional supports would be beneficial in other LTC facilities and therefore further studies are necessary. Further exploration is limited by the fact that only a few healthcare facilities have adopted the particular EPHR examined within this study and none of them are LTC facilities. Thus, EPHR adoption in Canada, particularly within Ontario remains low despite the growing body of literature identifying the benefits associated with EPHR access.

The findings within this study were mixed with respect to the role of an EPHR as an effective communication tool. Many family members indicated that it could support the communication of healthcare information, however some participants reported that it may impair communication exchange with staff. A few family members raised the specific issue that it may compromise opportunities for face to face exchange, which were already quite limited. Communication concerns have been identified in several other studies that have examined the patients' perspective.[21,26–29] For example, Tang and Lansky (2005) and Hassol *et al.* (2004) reported that information access can be accompanied by specific barriers linked to the in-person nature of the exchange.[21,26] Tang and Lansky (2005) indicated that information can often go undelivered because of the "barriers" placed by an in-person access requirement, which may be avoided with an EPHR. However, similar to the findings within the current study these authors also determined that technology such as EPHRs can also enhance communication channels, providing greater opportunities for the sharing of important health information that can support the patient/caregiver partnership.[21] They suggested that a system that integrates EPHRs with EHRs could allow for sharing of information and enable monitoring between patients and professionals to improve knowledge transfer between the various provider's and the patient and their health data.[21,27,28]

Additional EPHR concerns were highlighted that were linked to the sensitive nature of personal healthcare information, which have been identified in several other studies.[13,23,42–50] One third of family members in the current study reported concerns associated with confidentiality and security when considering the implementation of an EPHR. For example, concerns about security of personal information were found at the top of a list of concerns linked with an EPHR in a study conducted by the Markle Foundation (2006). Although the reported frequency of concern associated with privacy, security and confidentiality related to the adoption of an EPHR varies between studies, it is evident that these issues remain a concern amongst many different stakeholder groups, both nationally and internationally.[51]

Within the international literature EPHR access remains a complex issue, however several studies offer useful recommendations that can be applied.[38,41,44,51–55] Halamka, Mandl and Tang (2008) closely examined these EPHR access challenges.[41] Upon examining three case studies, they determined that there were some critical questions, similar to those examined within the current study, which should be examined when considering the adoption of an EPHR.[43] The key questions identified were: 1) Should the entire problem list be shared? 2) Should all laboratory and diagnostic tests be shared? and finally 3) Should clinical notes be shared? No clear answers were provided within the study, however they provided some suggestions on how other researchers could chose to address these questions and/or their recommendations from experience with EPHRs in their own health care settings.

As well, there findings offered additional EPHR recommendations that should be considered independent of the determined access type.[41] The EPHR recommendations were outlined as follows; consideration should be given to elements that will assist with the translation of medical terminology to promote a richer patient understanding of the information available, protocols for the release of different types of test results should be adopted, and specifications should be set for the completion of clinical notation by healthcare practitioners.[41] These recommendations should be considered for the EPHR implementation within this LTC setting and the associated impact of each of them should be studied.

While the study provided insight regarding the EPHR concerns of caregivers, there were a few limitations associated with the study that must be highlighted. First, the sample size was too small (158 family members with a response rate of 41%) to allow for generalizations regarding the findings beyond the institution. As such, future studies should aim

to expand the sample size within the institution and beyond to include other LTC facilities, which is currently limited given that EPHR implementation has been very low within the country. Secondly, the questionnaire administered to family members was comprised of both closed and open ended questions. Although the open-ended approach provided the opportunity to garner rich detailed information, the limitation associated with using open-ended questions is that they can potentially result in a categorization of responses and may presuppose a specific interpretation erroneously. To limit the impact of this, the questions were framed in a neutral tone and the survey was self-administered.

Finally, the bulk of the literature suggests that many stakeholders should be involved in all stages, including the planning, construction, implementation and evaluation of an EPHR.[32,38,43] Within the literature, it is indicated that the principle users should be given key priority, which in the current study were family members. As such, family members should continue to play an active role in the continuous process improvement and the post-implementation evaluation of the EPHR. In fact, this should be the case for any healthcare setting where family members may have primary access and key decision making roles surrounding the delivery of patient care.

REFERENCES

[1] Canada Health Infoway n.d.a. Consumer Health Solutions. [cited 2013 February 26]. Available from: http://dx.doi.org/10.1186/1471-2261-3-9

[2] Gangnon MP, Shaw N, Sicotte C, *et al*. Users' perspectives of barriers and facilitators to implementing EHR in Canada: A study protocol. Implement Sci. 2009; 4(20). http://dx.doi.org/10.1186/1748-5908-4-20

[3] Romanow RJ. Building on Values: The Future of Health Care in Canada - Final Report. Ottawa: Commission on the Future of Health Care in Canada; 2002. PMid: 11861605.

[4] Alvarez R. The electronic health record: a leap forward in patient safety. Healthc Pap. 2004; 5: 33-36. PMid: 16278533. http://dx.doi.org/10.12927/hcpap.2004.16862

[5] Flegel K. Getting to the electronic medical record. Can Med Assoc J. 2008; 178. http://dx.doi.org/10.1503/cmaj.080139

[6] Morgan MW. In pursuit of a safe Canadian healthcare system. Healthc Pap. 2004; 5: 10-26. PMid: 16278531. http://dx.doi.org/10.12927/hcpap.2004.16860

[7] Chaudhry B, Wang J, Wu S, *et al*. Systematic review: impact of health information technology on quality, efficiency, and costs of medical care. Ann Intern Med. 2006; 144: 742-752. PMid: 16702590. http://dx.doi.org/10.7326/0003-4819-144-10-200605160-00125

[8] Delpierre C, Cuzin L, Fillaux J, *et al*. A systematic review of computer-based patient record systems and quality of care: more randomized clinical trials or a broader approach? Int J Qual Health Care. 2004; 16: 407-416. PMid: 15375102. http://dx.doi.org/10.1093/intqhc/mzh064

[9] Lewis M, Baxter R, Pouder R. The development and deployment of electronic personal health records. J Health Organ Manag. 2013; 27: 577-600. PMid: 24341178. http://dx.doi.org/10.1108/JHOM-07-2012-0144

[10] Earnest MA, Roos SE, Wittevrongel L, *et al*. Use of a patient-accessible electronic medical record in a practice for congestive heart failure: patient and physician experiences. J Am Med Inform Assoc. 2004; 11: 410-417. PMid: 15187074. http://dx.doi.org/10.1197/jamia.M1479

[11] Scalise D. Patient satisfaction and the new consumer. Hosp Health Netw. 2006; 80: 57-62. PMid: 17236457.

[12] Ball MJ, Smith C, Bakalar RS. Personal Health Records: empowering consumers. J Healthc Inform Manag. 2007; 21: 76-86. PMid: 17299929.

[13] Krohn R. The consumer-centric personal health record - It's time. J Health Organ Manag. 2007; 21: 20-23.

[14] Canada Health Infoway n.d.b. Electronic Health Records 2015: Canada's next generation of health care at a glance. [cited 2013, February 26]. Available from: http://v1.theglobeandmail.com/partners/free/infoway/pdf/2015%20Health%20care%20at%20a%20glance%20EN.pdf

[15] National Alliance for Health Information Technology. Defining Key Health Information Technology Terms. [cited 2013 Dec 19]. Available from: http://www.hhs.gov/healthit/documents/m20080603/10_2_hit_terms.pdf

[16] Office of the Auditor General of Canada 2010, Electronic Health Records in Canada: An overview of Federal and Provincial Audit Report. [cited 2013 October 5]. Available from: http://www.oag-bvg.gc.ca/internet/docs/parl_oag_201004_07_e.pdf

[17] Roth C, Foraker RE, Payne PRO, *et al*. Community-level determinants of obesity: harnessing the power of electronic health records for retrospective data analysis. BMC Medical Informatics and Decision Making. 2014; 14: 14-36. PMid: 24886134. http://dx.doi.org/10.1186/1472-6947-14-36

[18] Merriam SB. Qualitative research: A guide to design and implementation. San Francisco: Jossey-Bass; 2009.

[19] Ziebland S, McPherson A. Making sense of qualitative data analysis: an introduction with illustrations from DIPEx (personal experiences of health and illness). Med Educ. 2006; 40: 405-414. PMid: 16635119. http://dx.doi.org/10.1111/j.1365-2929.2006.02467.x

[20] Ueckert F, Goerz M, Ataian M, *et al*. Empowerment of patients and communication with health care professionals through an electronic health record. Int J Med Inform. 2003; 70: 99-108. http://dx.doi.org/10.1016/S1386-5056(03)00052-2

[21] Tang PC, Lansky D. The missing link: bridging the patient-provider health information gap. Health Affairs. 2005; 24: 1290-1295. PMid: 16162575. http://dx.doi.org/10.1377/hlthaff.24.5.1290

[22] Taylor H, Leitman R. Study reveals big potential for the internet to improve doctor-patient relations. Health Care News. 2001. [cited 2013 March 10]. Available from: http://www.harrisinteractive.com/news/newsletters/healthnews/HI_HealthCareNews-V1-Issue1.pdf

[23] Patel VN, Abramson E, Edwards AM, *et al*. Consumer attitudes toward personal health records in a Beacon community. Am J Manag Care. 2011; 17: e104-120. PMid: 21774099.

[24] Markle Foundation. Survey finds Americans want electronic personal health information to improve own health care. 2006. [cited 2013 October 5]. Available from: http://www.markle.org/publications/1214-survey-finds-americans-want-electronic-personal-health-information-improve-own-hea

[25] Udem T. Consumers and health information technology: A national survey, California HealthCare Foundation & Lake Research Partners, Oakland, CA. 2010.

[26] Hassol A, Walker JM, Kidder D, *et al*. Patient experiences and attitudes about access to a patient electronic health care record and linked web messaging. J Am Med Inform Assoc. 2004; 11: 505-513. PMid: 15299001. http://dx.doi.org/10.1197/jamia.M1593

[27] Thielst CB. The new frontier of electronic, personal, and virtual health records. J Healthc Manag. 2007; 52: 75-78. PMid: 17447534.

[28] Urowitz S, Wiljet D, Apatu E, *et al*. Is Canada ready for patient accessible electronic health records? A national scan. BMC Med Inform Decis Mak. 2008; 8: 1-7. PMid: 18652695. http://dx.doi.org/10.1186/1472-6947-8-33

[29] Boris JR. Commentary on the adoption of the electronic health record. Cardiol Young. 2010; 20 Suppl 3: 140-142. http://dx.doi:10.1017/S1047951110001204r

[30] Ralston JD, Carrell D, Reid R, *et al*. Patient web services integrated with a shared medical record: patient use and satisfaction. J Am Med Inform Assoc. 2007; 14: 798-806. PMid: 17712090. http://dx.doi.org/10.1197/jamia.M2302

[31] Weingart SN, Rind D, Tofias Z, *et al*. Who uses the patient internet portal? The Patient Site experience.J Am Med Inform Assoc. 2006; 13: 91-95. PMid: 16221943. http://dx.doi.org/10.1197/jamia.M1833

[32] Simpson R. Putting the Patient in Patient-Centered Care: What It Can Do. In: 18th annual Summer Institute in Nursing Informatics Conference; 2008 July 14-19; Baltimore, MD.

[33] McAiney CA, Haughton D, Jennings J, *et al*. A unique practice model for Nurse Practitioners in long-term care homes. J Adv Nurs. 2008; 62: 562-571. PMid: 18489449. http://dx.doi.org/10.1111/j.1365-2648.2008.04628.x

[34] Thede T. Informatics: Electronic Personal Health Records: Nursing's Role. [cited 2013 October 5]. Available from: http://www.nursingworld.org/MainMenuCategories/ThePracticeofProfessionalNursing/Health-IT/Electronic-Personal-Health-Records.html

[35] Halamka J, Overhage JM, Ricciardi L, *et al*. Exchanging health information: local distribution, national coordination. Health Aff (Millwood). 2005; 24: 1170-9. PMid: 16162560. http://dx.doi.org/10.1377/hlthaff.24.5.1170

[36] Kogut SJ, Goldstein E, Charbonneau C, *et al*. Improving medication management after a hospitalization with pharmacist home visits and electronic personal health records: an observational study. Drug Healthc Patient Saf. 2014; 6: 1-6. PMid: 24465136. http://dx.doi.org/10.2147/DHPS.S56574

[37] Vogeli C, Shields AE, Lee TA, *et al*. Multiple chronic conditions: prevalence, health consequences, and implications for quality, care management, and costs. J Gen Intern Med. 2007; 22 Suppl: 391-395. PMid: 18026807. http://dx.doi.org/10.1007/s11606-007-0322-1

[38] Wiljer D, Urowitz S, Apatu E, *et al*. Patient accessible electronic health records: exploring recommendations for successful implementation strategies. J Med Internet Res. 2008; 10: e1-13. PMid: 18974036. http://dx.doi.org/10.2196/jmir.1061

[39] Freedman JE, Becker RC, Adams JE, *et al*. Medication Errors in Acute Cardiac Care. Circ. 2002; 106: 2623-2629. http://dx.doi.org/10.1161/01.CIR.0000037748.19282.7D

[40] Roblin DW, Houston TK, Allison JJ, *et al*. Disparities in use of a personal health record in a managed care organization. J Am Med Inform Assoc. 2009; 16: 683-689. PMid: 19567790. http://dx.doi.org/10.1197/jamia.M3169

[41] Halamka JD, Mandl KD, Tang PC. Early experiences with personal health records. J Am Med Inform Assoc. 2008; 15: 1-7. PMid: 17947615. http://dx.doi.org/10.1197/jamia.M2562

[42] McCartney PR. The electronic personal health record. MCN Am J Matern Child Nurs. 2008; 33: 390. http://dx.doi.org/10.1097/01.NMC.0000341262.00620.dc

[43] Nijland N, van Gemert-Pijnen J, Boer H, *et al*. Evaluation of internet-based technology for supporting self-care: problems encountered by patients and caregivers when using self-care applications. J Med Internet Res. 2008; 10: 1-12. PMid: 18487137. http://dx.doi.org/10.2196/jmir.957

[44] Tang PC, Ash JS, Bates DW, *et al*. Personal Health Records: definitions, benefits, and strategies for overcoming barriers to adoption. J Am Med Inform Assoc. 2006; 13: 121-126. PMid: 16357345. http://dx.doi.org/10.1197/jamia.M2025

[45] Pagliari C, Detmer D, Singleton P. Potential of electronic personal health records. BMJ. 2007; 335: 330. PMid: 17703042. http://dx.doi.org/10.1136/bmj.39279.482963.AD

[46] Detmer D, Bloomrosen M, Raymond B, *et al*. Integrated Personal Health Records: Tranformative Tools for Consumer Centric Care. BMC: Med Inform Decis Mak. 2008; 8: 45-50. PMid: 18837999. http://dx.doi.org/10.1186/1472-6947-8-45

[47] Archer N, Fevrier-Thomas U, Lokker C, *et al*. Personal Health Records: A Scoping Review. J Am Med Inform Assoc. 2011; 18: 515-52. PMid: 21672914. http://dx.doi.org/10.1377/hlthaff.24.5.1170

[48] Yau G, Williams A, Brown J. Family physicians' perspectives on personal health records. Can Fam Physician. 2011; 57: 178-84.

[49] Krist A. A Vision for Patient-Centered Health Information Systems. JAMA. 2011; 305: 365-377. PMid: 21245186. http://dx.doi.org/10.1001/jama.2010.2011

[50] Williams J, Weber-Jahnke J. The Regulation of Personal Health Records in Canada. Canadian Journal of Law and Technology. 2010; 8(2): 267-75.

[51] Carrión SI, Fernández-Alemán JL, Toval A. Are Personal Health Records Safe? A Review of Free Web-Accessible Personal Health Record Privacy Policies J Med Internet Res. 2012; 14(4): e114. PMid: 22917868. http://dx.doi.org/10.2196/jmir.1904

[52] Wilson EV. Patient-Centered E-Health. Medical Information Science Reference; Hershey, PA. 2009. http://dx.doi.org/10.4018/978-1-60566-016-5

[53] Lober WB, Zierler B, Herbaugh A, *et al*. Barriers to the use of a Personal Health Record by an elderly population. AMIA 2006 Symposium Proceedings. [cited 2013 May 27]. Available from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1839577/pdf/AMIA2006_0514.pdf

[54] Heubusch K. Piecing together the PHR. J AHIMA. 2007; 78: 28-32. PMid: 17455842.

[55] Byczkowski TL, Munafo JK, Britto MT. Family perceptions of the usability and value of chronic disease web-based patient portals. H Inf J. 2014; 20: 151-162.