

**Access Forum: From Populous to Policy**

An Exploration of Canadian Readiness for Implementation of  
Patient Accessible Electronic Health Records (PAEHR)  
and  
Recommendations for a National Agenda on PAEHR

A report submitted by the:  
**Canadian Committee for Patient Accessible Electronic Health Records**

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## Executive Summary

In order to encourage patients to become active participants in managing their health care, the Canadian Committee for Patient Accessible Electronic Health Records (CCPAEHR) conducted a survey to determine how ready Canadian general hospitals are for the implementation and use of electronic health records (EHRs). A National Scan was conducted and Chief Executive Officers (CEOs) of various acute care and public hospitals in Canada were sent an e-mail with a link to an electronic survey designed to describe current practices for maintaining patient health records (PHRs) and providing access to those records at their respective institutions. There is a growing interest in providing patient access to health and medical records. Previous studies reported that patients desire access to their EHR. Providing access to one's health record can help patients understand their condition and can potentially improve patient-provider communication with little or no disruption to clinical operations.

Eighty-three hospitals responded to the survey for a response rate of 39%. Most of the responses came from single hospitals; however, over half were part of a larger health care system. Although the majority of respondents were from Ontario, there was representation from all over the country. Just over half (54.2%) of hospitals surveyed reported having some sort of EHR, but 97.6% indicated that it was not the only method for recording patient information. Access to funding and better information were identified as the two most important factors driving the adoption of an EHR. The cost and the time needed for development and implementation of EHRs were identified as the major barriers to implementation. Although very few of the institutions had surveyed their providers or patients on providing access to their EHR, the overall perception was that staff would be less likely to want to provide access and would only want to provide partial access, whereas patients strongly desire access to the full record.

In conjunction with the national scan, the CCPAEHR hosted a one-day workshop to bring members of CCPAEHR and key stakeholders together in a workshop setting to generate national recommendations for the implementation and adoption of Patient Accessible Electronic Health Records (PAEHRs). The purpose of the workshop was to share these data to stimulate discussion resulting in the development of national recommendations on PAEHRs, and to identify research priorities for providing patients with access to their EHR. The workshop was organized around four thematic areas: 1) providing patient access to EHRs, 2) maintaining privacy and confidentiality related to PAEHRs, 3) patient education and navigation of a PAEHR, and, 4) strategies for managing institutional change. Recommendations were proposed and refined in each of the four thematic areas.

As EHRs become more common, several organizations are beginning to explore the possibility of responding to patient needs for clinical information by providing patient access to their EHRs. Although many will agree that patients should have access to their health information, the best way to actualize this is still being debated. Before widespread use of patient access to the EHR can become a reality, it is paramount that we resolve privacy and confidentiality issues and the questions of ownership versus custodianship. Once these and other issues are resolved, there are a number of organizational and research issues that need to be addressed. These challenges should not hinder the movement towards the implementation of patient access to the EHR, but should instead be viewed as motivators for creating the best possible product to meet all of the stakeholders' needs.

## Introduction

Providing access to individual health records helps educate, engage and empower patients in the health care encounter, which, in turn, is associated with positive outcomes experienced by the patients (Paterson 2001; Wallerstein 2006). There is the growing global trend of adopting legislation to ensure that patients are able to access, review and amend their medical record (Kluge 1993; Mathews 1998; Mitchell 1998; Blechner and Butera 2002; Dietzel 2002; Pyper, Amery et al. 2002; Chasteen, Murphy et al. 2003; Jones, Cawsey et al. 2003; France 2004; Ishikawa, Konishi et al. 2004; Beardwood and Kerr 2005; Harman 2005), and a greater emphasis has been placed on a more consumerist approach to health care. This requires that patients assume a more involved role in the management of their health care information (Eysenbach 2000). As a result, health care providers, academics and the public have begun to express a growing interest in providing people with access to their health and medical records. This movement has emerged during a period characterized by a proliferation of Information and Communication Technologies (ICTs). The adoption of ICTs by the health and medical community has broadened the scope of how and where health care and related information can be provided. While the discussions on and experiments with giving patients access to their health records precede the Internet era (Coleman 1984; Baldry, Cheal et al. 1986; Gilhooly and McGhee 1991), ICTs greatly facilitate access to this information, most commonly through the Internet (Ross and Lin 2003; Ross and Lin 2003; Ross, Moore et al. 2004; Pai and Lau 2005), and allow linking with tailored health information (Eysenbach 2000). Due to growing consumerist tendencies of patients in the health care system, and the widespread use of the Internet, it is expected that there will be an increase in the number of individuals who chose to review and interact with their medical record on an ongoing basis. Mechanisms, such as policies and procedures, are therefore necessary to ensure the success of moving towards a system that supports the wide scale use of patient-accessible electronic health records (PAEHRs).

In an attempt to meet this need, the Canadian Committee for Patient Accessible Electronic Health Records (CCPAEHR)<sup>1</sup> undertook a two-part project with the intent of 1) scanning the country to determine hospital readiness for the implementation and use of PAEHRs, and 2) assembling a workshop of key stakeholders in the field of the electronic health records (EHRs) and PAEHRs. This workshop was designed to explore options for Canada related to providing patient access to their EHRs, maintaining the privacy and confidentiality of EHRs, providing patient navigation and education related to details of PAEHRs, and exploring institutional strategies for change to support the adoption of patient access to their EHRs. This report will present a summary of the literature on patient access to their health record in both paper and electronic format, as a means of framing the project agenda. A summary of results on EHRs and PAEHR readiness and recommendations drafted at the workshop supported by the current literature and international experience will also be presented.

<sup>1</sup> The CCPAEHR is a group of Canadian researchers, clinicians, information specialists and educators working together to promote patient access to and involvement with electronic health records.

## **PART I - Background and Summary of the Literature**

### *I. Electronic Health Record (EHR):*

An Electronic Health Record (EHR) is an individual's health record that is accessible online from many separate, interoperable automated systems within an electronic network (Canada 2004). An EHR enables the electronic integration of health care providers and enables the retrieval of information about patients when and where it is most needed. Both universal access to an EHR, and the integration among providers has been shown to result in the reduction of medical error and healthcare costs as well as in quality improvement (Bates, Leape et al. 1998; Petersen, Orav et al. 1998; Agrawal 2002; Valdes, Kibbe et al. 2004; Hillestad, Bigelow et al. 2005). This in part may be the result of electronic records being both more complete and legible than hand written records (CHI 2005).

Some institutions support patient accessible EHRs (PAEHRs), most commonly through online web-based patient portals and many have advocated for the use of PAEHRs. There is already a growing body of literature that has begun to explore the benefits and barriers to PAEHRs. Effective implementation and use of patient access to the EHR, however, requires that all stakeholders support the initiative. There are three key levels of stakeholders: the institutional level, the provider level, and the patient/consumer level (Studer 2005).

In a large-scale study that examined patients' experiences and attitudes about access to their EHR and linked web messaging, the majority of participants found that accessing their record was easy and that their medical record was complete and accurate. In addition, the majority of participants found the information in the record to be understandable. Only a few respondents were concerned about confidentiality or about the possibility of discovering unfavorable test results (Hassol, Walker et al. 2004). A study of providing web-based health information to men with prostate cancer reported that 75% of respondents desired an alternate way of accessing their health record, and the Internet was ranked as one of the most desired methods (Pai and Lau 2005). Providing access to the PAEHR has the additional benefit of being able to link the record to educational resources to help patients understand the information (Ross and Lin 2003; Ross, Moore et al. 2004; Pai and Lau 2005). Electronic access to health and medical records is achievable without compromising patient privacy and security (Cimino, Patel et al. 2001; Masys, Baker et al. 2002; Pyper, Amery et al. 2002; Goldberg, Ralston et al. 2003; Pyper, Amery et al. 2004). There is also research that suggests that making an EHR accessible to patients may empower them (Ueckert, Goerz et al. 2003; Ralston, Revere et al. 2004); however, this area of research is still in its formative stage and many issues still require extensive exploration (Ralston, Revere et al. 2004; Winkelman, Leonard et al. 2005).

Organizational factors can influence the effectiveness of an EHR system implementation (Studer 2005). These organizational factors include 1) management support with a strong public commitment to support the endeavor (Dansky, Gamm et al. 1999; Chiang and Starren 2002; Studer 2005), 2) the availability of financial resources including start-up funds and sufficient monetary resources to support ongoing operations and a strong financial base to support reductions in productivity during training and learning periods (Townes, Benson et al. 2000; Wager, Lee et al. 2000; Studer 2005), 3) a climate that embraces change and that values innovation (Retchin and Wenzel 1999; Studer 2005), and 4) the existence of policies and practices related to the implementation

and use of an institutional EHR including but not limited to, training and ongoing, on-site technical support (Tonnesen, LeMaistre et al. 1999; Wager, Lee et al. 2000; Aaronson, Murphy-Cullen et al. 2001; Studer 2005).

The published evidence is strongly in support of wide scale implementation of PAEHRs. The success in the implementation and use of these records requires a thorough consideration of four thematic areas: developing approaches to support patient access to an EHR, maintaining privacy and confidentiality of EHRs, providing patient education for interpretation and navigation of an EHR, and supporting institutional change (Leonard 2005). These four topic areas are summarized in the policy briefs found in appendices A – D.

## *II. Benefits of Patient Accessible Records*

The benefits of providing patient access to health and medical records, in either a paper or an electronic format, have been well documented. Access to one's medical record can potentially: 1) enhance patients' understanding of their condition (Cimino, Patel et al. 2002), 2) empower individuals to become active participants in their own care (Stein, Furedy et al. 1979; Moehr and Grant 2000; Ueckert and Prokosch 2002), 3) result in better medical management (McGhee, Hedley et al. 1990; Ross, Moore et al. 2004), 4) lead to more effective provider-patient communication (Elbourne, Richardson et al. 1987; Homer, Davis et al. 1999; Cimino, Patel et al. 2002; Earnest, Ross et al. 2004) and, 5) may improve satisfaction and outcomes (Earnest, Ross et al. 2004; Wu, Delgado et al. 2005), possibly through improved adherence to health promotion recommendations (Bronson and K. 1986). Providing patient access to medical records is also cited as a way of striving towards a model of patient-centred care (Gerteis, Edgman-Levitan et al. 1993), and has been shown to result in little to no disruption in clinical operations (Cimino, Patel et al. 2001).

People are interested in viewing their medical records, either in full or in part (Ross and Lin 2003; Pyper, Amery et al. 2004; Pyper, Amery et al. 2004). Fowles et al. reported that 77% of participants surveyed indicated that they were either somewhat or very interested in reading their clinical record (Fowles, Kind et al. 2004). Different reasons have been cited for why patients want access to their medical record, including the need for greater understanding of their disease (Cimino, Patel et al. 2002), improved communication, and an increased sense of control (Ross and Lin 2003). The greatest predictors of a patient's desire to read the medical record are the number of benefits that they perceive in accessing the records and their information-seeking behaviours, including Internet usage, rather than clinical characteristics or educational levels (Ross and Lin 2003; Fowles, Kind et al. 2004).

The numerous potential benefits of providing people with access to their health and medical records have been identified (Pyper, Amery et al. 2002; Jones 2003; Ross and Lin 2003; Earnest, Ross et al. 2004). Published evidence suggests that there is an increase in patient satisfaction and improved patient compliance with self-care (Ross, Moore et al. 2004; Winkelman, Leonard et al. 2005) when given access to the medical record. Others reported that potentially serious safety concerns were identified when patients found inaccuracies in the medical record (Stevens, Stagg et al. 1977). A clinical trial by Ross et al., reported that when patients were given access to their written health records, there were modest benefits in the area of doctor-patient communication and minimal risk of harm (Ross, Moore et al. 2004). A study of men with prostate cancer

found that providing these men with timely access to their health record resulted in enhanced ability to understand their condition and participate in shared medical decision-making (Pai and Lau 2005). Most patients have responded positively to accessing their records and little disruption to clinical operations have been reported (Cimino, Patel et al. 2001). One health care center's experience also suggests that allowing patients to view their medical record reduces anxiety by removing the fear of what may have been "hidden" or not communicated by the physician (Tufo, Bouchard et al. 1977).

## **PART II -National Scan**

### The National Scan

#### **Introduction**

The National Scan was conducted as a means of evaluating the readiness of Canadian general hospitals for implementation and use of institutional EHRs. The results from the scan were presented at the Patient Accessible Electronic Health Records Workshop, held in Toronto on October 19, 2006, and helped to frame the discussion of the day. The findings provided a description of the current Canadian status on EHR-readiness and the necessary data for drafting the recommendations presented in this document.

#### *Research Agenda:*

The scan was developed with the intent of answering three broad research questions:

- 1) What is the status of official policies on the implementation and use of EHRs by patients in Canadian public general hospitals?
- 2) What are the necessary institutional characteristics for the successful implementation of a program that supports the use of and access to EHRs by patients?
- 3) What is the current status of data on provider or patient preferences regarding the implementation and use of an EHR?

#### **Methods**

##### *Study Population*

A list of potential participants was generated from the 2005 Scott's Canadian Medical Directory. Eligibility required a designation of either public or acute care hospital, and an active email address for the institution's Chief Executive Officer (CEO).

##### *Research Design*

Based on a review of the literature, a questionnaire was created to measure national readiness for the adoption and implementation of patient access to an EHR. The questionnaire included 5 sections, including current record keeping practices using a paper-based record, current record-keeping practices using an EHR, the information technology infrastructure to support an EHR, and perceptions about providing patient access to an EHR. The questionnaire was reviewed, and tested for face validity by members of the CCPAEHR.

Data collection took place over an eight-week period (August 2006 – September 2006). CEOs of eligible institutions were emailed a letter of introduction (appendix E) and a link to the electronic questionnaire (in either English [appendix F] or French [see appendix G]). The CEO was then asked to complete the questionnaire and submit it within two weeks of receipt. In addition, the CEO was asked to forward the link for the questionnaire to the chiefs of medicine, nursing and informatics, or the individual who s/he thought would be most appropriate to respond.

A reminder email message was sent two weeks after initial contact was made, and again, three weeks prior to the close of study date. Data collection closed on September 29, 2006.

*Analytic Approach:*

Data were analyzed over a two and a half week period, using both Questionpro.com and the SPSS statistical analysis package. Descriptive statistics were used to summarize the basic features of the data, and cross tabulations were used to show the relationship between variables.

**Results**

In total, 213 emails were sent to CEOs of Canadian general and acute care hospitals. There was a 39% response rate (83/213 hospitals responded to the survey).

*Demographics:*

While the majority of respondents were from Ontario 58.8% (n=30), there was representation from across the country. Most of the respondents were Managers of Departments of Health Records (58.3%). An additional 22.2% identified themselves as Managers of Health Records and Privacy. Half of the responses came from institutions with fewer than 100 beds, but there were responses from a number of medium-sized and larger hospitals as well. Table 1 summarizes these results. There was only one respondent who answered on behalf of a health care system (which included 13 hospitals in total), but over half (58.5%) indicated that their hospital was part of a larger health care system.

**Table 1: Demographics**

<b>Demographic</b>	<b>Demographic</b>	<b>Respondents %</b>
<b>Location</b> N = 50	Ontario	58
	British Columbia	16
	Manitoba	10
	Alberta	8
	North West Territories	4
	New Brunswick	2
	Nunavut	2
<b>Role</b> N = 54	Chief Executive Officer	9.4
	Chief of Medicine	3.8
	Chief of Nursing	11.3
	Chief Information Officer	7.6
	Other/Unknown	67.9*
<b>Hospital size</b> N = 51	Less than 100	49.0
	100 to 400	33.3
	More than 400	17.7

*\*Other roles most commonly included Managers of Health Records, Health Information Services or Privacy Officers.*

### *The Paper Record*

Almost all respondents (95%) reported that their institution uses a paper-based patient record, and that patients are permitted to access this record (98.2%). In order to view the paper record, over half (64.9%) of the respondents said that patients have to request a copy of the record from the medical records department (or an equivalent). When the paper record is requested, most commonly only the sections requested are presented to the patient, but 42% of respondents indicated that the full record is provided. The time taken to fill patients' requests to access their record varied from less than one day to almost one month. Most commonly, 53.3% of requests are filled within 7 days. In the majority of institutions (71.1%) patients are charged a fee for accessing their paper record. Some institutions charge on a per-minute basis (\$6.75/15min and \$50/30 min.), while others charged a flat fee ranging from \$10 to \$106. Still others charged a certain amount per page - some with starting amounts in addition to the per-page fee.

### *The Electronic Record*

Just over half (54.2%) of hospitals surveyed reported having some sort of EHR, but 97.6% indicated that it was not the only method for recording patient information. There were very few institutions that had a predominately electronic record - only 2.4% of respondents had records that were between 91-100% electronic. Most hospitals (39%) had records that were 11-50% electronic (Table 2).

**Table 2: Percent of Patient Record that is Electronic**  
N = 41

<b>% Electronic</b>	<b>Respondents %</b>
0-10%	29.3
11-50%	39
51-90%	29.3
91-100%	2.4

Almost half (44.6%) of the respondents thought that their institution was "on track" with the rest of the country in terms of adoption and use of EHRs, while 35.4% indicated that their institution was behind on adoption and implementation and 12.3% indicated that they were ahead of the country. Very few institutions (7.7%) identified themselves as leaders in this area.

For hospitals that have an electronic record, adoption of an EHR was most commonly a recent phenomenon. Just over half (67.5%) of respondents reported an adoption of their EHR within the past 5 years (Table 3).

**Table 3: Time Since Adoption of EHRs**  
N= 43

Years	Respondents %
<1yr	16.3
>1yr	51.2
>5yrs	27.9
>10yrs	4.7

Funding for EHRs was predominately provided by the institution (Table 4).

**Table: 4 Sources of Funding to Support EHRs**  
N = 59

Funding Source	Respondents %
Institution	54.2
Industry	1.7
Research Grants	1.7
Donations	2.1
Province	11.8
National	3.5

Respondents were asked which, if any, of the following policies exist in their institution: 1) a formal policy that all patient data is recorded in the institutional EHR, 2) a formal policy on patient access to the institutional EHR, and 3) a policy regarding confidentiality of EHRs. In addition, respondents were asked if there was an informal policy regarding access to the institutional EHR. Responses are summarized in Table 5.

**Table 5: Policies Related to EHRs**

Type of Policy	N	Respondents %
All patient info must be recorded in an EHR	36	8.3
Patient access to the institutional EHR (formal)	33	39.4
Patient access to the institutional EHR (informal)	34	20.6
Maintaining confidentiality	32	96.9

Data were collected on factors driving and barriers impeding the adoption of an EHR. Access to funding and better information were identified as the two most important factors driving the adoption of EHRs. Consumer demand was identified as the least important (Table 6).

<b>Factors</b>	<b>N</b>	<b>Most Important</b>	<b>Important</b>	<b>Somewhat important</b>	<b>Less important</b>	<b>Least important</b>
Consumer demand	64	7.8	18.8	35.9	14	23.4
Provider demand	65	46.1	33.9	15.4	3.1	1.5
Executive leadership	65	36.9	35.4	21.5	1.5	4.6
Access to funding	66	63.6	18.2	10.6	6.1	1.5
Access to information	64	68.8	12.5	14.1	4.7	0

The cost and the time needed for development and implementation of an EHR were identified as the major barriers to implementation. Concerns regarding privacy were identified as important or somewhat important barriers to implementation (Table 7).

**Table 7: Key Barriers to Adoption of EHRs**

<b>Factors</b>	<b>N</b>	<b>Most Important</b>	<b>Important</b>	<b>Somewhat important</b>	<b>Less important</b>	<b>Least important</b>
Cost	66	74.2	18.1	6.1	0	1.5
Privacy concerns	65	26.1	27.7	30.8	12.3	3.1
Coordination of stakeholders	65	33.9	35.4	27.7	1.5	1.5
Education and training	65	26.1	26.1	30.8	13.9	3.1
Time and effort	66	57.6	28.8	7.6	4.6	1.5

Continuity and quality of care were identified as the primary benefits resulting from the presence of an EHR in the institution (Table 8).

**Table 8: Key Benefits of Having an EHR**  
N = 65

Benefits	Most Important	Important	Somewhat important	Less important	Least important
Patient safety	44.6	23	24.6	6.2	1.5
Workflow Efficiencies	38.5	38.5	12.3	10.8	0
Quality of care	58.5	26.2	13.9	1.5	0
Continuity of care	76.9	15.4	7.7	0	0

#### *Information Technology Infrastructure*

The majority of respondents (81.8%) reported that their IT infrastructure could support an EHR, but only 27.8% of respondents indicated that their IT infrastructure could support patient access to EHRs. A significant number of respondents (66.7%) said that their institution had plans to implement the appropriate IT infrastructure to support a PAEHR (Table 9). Respondents who described their plans for implementation, indicated that the efforts were part of a larger regional project, and that they were in the process of installing the necessary software and hardware to support the system. Reasons for not introducing PAEHRs included the lack of necessary funding, concerns over necessary clinical support for patients, concerns over privacy, the need to focus on training providers to use EHRs first, and the overall perception of the lack of demand and the lower priority placed on patient access.

**Table 9: IT Infrastructure**

Characteristics	N	Respondents %
Support EHR	64	81.8
Support patient access	52	27.8
Plan to implement IT to support PAEHR	50	66.7

None of the respondents indicated that they currently provide patient access to an EHR through the Internet (n=46). Few respondents, 15.6%, provide patient access to EHRs on hospital based computers, and 84.4% reported some other methods of patient access to EHRs, including access through the health records department, viewing the record together with a Health Information Management professional, or if deployed on a hospital computer by hospital personnel on behalf of the patient. When asked about the ability to provide multiple accesses to a single chart using unique passwords, 23.9% of respondents said this was possible in their institution.

*Perceptions about providing access to an EHR*

Only 3% of respondents had conducted any formal survey of staff perceptions about providing patient access to an EHR. None of the respondent institutions had conducted a survey of patient perceptions around accessing EHRs. Respondents did, however, provide their opinion on perceived staff and patient willingness to give or gain access to an EHR. Very few, 3.6%, respondents thought that staff would be willing and eager to provide patient access to their EHRs. Just over one-quarter (28.6%), thought that staff would be hesitant but willing and 17.9% thought that staff would support partial access, while 50% of the respondents were unsure of the staff's perceptions or that no survey had been conducted (Table 10). Respondents were also asked to give their opinions on patients' perceptions regarding access to their EHRs. Less than half of respondents thought that patients would be eager (17%) or hesitant (17%) to access their EHR. Very few (3.8%) respondents indicated that they thought patients would only want partial access (Table 10). The majority of respondents were unable/unwilling to speculate on either provider or patient perception about patient access to an EHR.

**Table 10: Perceptions about Providing Access to EHRs**

<b>Desire</b>	<b>Provider % N = 56</b>	<b>Patient % N = 53</b>
Willing/Eager	3.6	17
Hesitant	28.6	17
Partial Only	17.9	3.8
Don't Know	50	62.3

Health care professionals' willingness to provide access appeared to depend on their role in their institution. Very few CEOs, Chiefs of Nursing and Managers of Health Records departments thought that staff would be open and willing to provide patient access. These results are summarized in table 11.

**Table 11:**  
**Perceptions about Providing Access to EHRs by Respondent's Role**

<b>Role</b>	<b>N</b>	<b>Unknown %</b>	<b>Partial Access %</b>	<b>Hesitant %</b>	<b>Open and willing %</b>
CEO	6	16.7	16.7	50	16.7
CIO	5	0	40	60	0
Chief of Medicine	2	0	50	50	0
Chief of Nursing	5	80	0	0	20
Health Records	18	44.4	22.2	27.8	5.6
Privacy	10	40	20	40	0
Risk Management	3	66.7	0	33.3	0

When asked which elements of an EHR providers would be willing to grant access to, a quarter responded test results. When asked which elements patients would want access to, a quarter responded the full record (Table 12).

**Table 12: Perceptions about accessible elements of EHRs**

<b>Elements of the EHR</b>	<b>Provider % N = 84</b>	<b>Patient % N = 68</b>
Full Record	10.7	25
Tests Results	25	16.2
Diagnosis	20.2	13.2
Pathology Reports	10.7	5.9
Clinician Notes	2.4	2.9

*Institutional Readiness and Support for Patient Accessible EHRs*

About half (46.9%) of the respondents thought that their institution was moderately supportive of PAEHRs (Table 13). The majority of respondents, 79.6% reported no institutional steering committee for providing patients with access to an EHR. Half (54.6%) of the respondents reported that their institution was moderately effective at managing change. Very few respondents (3.6%) thought that their institution could not readily manage change.

**Table 13: Management's Level of Support Regarding PAEHRs**  
N = 48

Level of Support	Respondents %
Not very supportive	10.4
Not supportive	12.5
Moderately supportive	47.9
Supportive	18.8
Very Supportive	10.4

Respondents were asked to indicate the importance of several barriers to effectively giving patients access to EHRs in their institution. Hospital financial resources were identified as the most important barrier. Clinician buy-in and patients' computer literacy were also considered very important (Table 14).

**Table 14: Importance of Barriers to PAEHRs**  
N = 54

Barriers	Very Important %	Important %	Moderately %	Not Important %	Not Very Important %
Finances	86.7	9.2	16.7	3.7	3.7
Clinician buy-in	50	27.8	14.8	7.4	0
Patient Access to Computers	27.8	22.2	33.3	11.1	5.6
Patient Computer Literacy	48.1	13	22.2	9.3	7.4

#### *Educational Support*

Over three quarters (79.3%) of respondents indicated that their hospital provides disease-specific educational materials. Only 7.6% of the institutions provide educational materials as part of the EHR, and no respondents said that they provide educational materials specifically designed to help patients navigate or understand the content of the EHR.

#### **Ethical Considerations**

By completing the questionnaire, subjects gave their implicit consent to participate. This project was intended to gather information about readiness for the implementation and use of patient accessible EHRs. Individual observation and evaluation was not the focus of this project, so the risk of privacy invasion and emotional turmoil was low.

### **PART III - Patient Accessible Electronic Health Records Workshop**

In conjunction with the national scan, the CCPAEHR hosted a one-day workshop to bring members of CCAPEHR and key stakeholders (a list of participants is provided in appendix H.) together in a workshop setting to generate national recommendations for the implementation and adoption of PAEHRs. The discussion was guided by the results obtained from the national scan, four policy briefs that were developed through an iterative collaborative process by members of the CCPAEHR and experts in the field of PAEHRs, as well as presentations from invited national and international experts. The purpose of the workshop was to share this data to stimulate discussion resulting in the development of national recommendations on PAEHRs, and to identify research priorities for providing patients with access to their EHR.

The workshop was organized around four thematic areas with the intent of developing six to eight recommendations for each of the four themes. The themes identified by members of CCPAEHR were: 1) providing patient access to their EHR, 2) maintaining privacy and confidentiality related to PAEHRs, 3) patient education and navigation of PAEHR, and, 4) strategies for managing institutional change. Keynote speaker, Dr. Kevin Leonard, University of Toronto, Department of Health Policy, Management and Evaluation and the Centre for Global eHealth Innovation, University Health Network, spoke on, *A Prescription for Patience: Patients gaining access to their Electronic Health Records (EHRs)* (Leonard 2005). In addition, speakers with expertise in each of the four areas were invited to address the workshop. Dr. James Walker from Geisinger Health System spoke on Geisinger's experience with patient access to an EHR, Dr. Miyo Yamashita<sup>2</sup>, Anzen Consulting Inc., spoke on privacy and confidentiality of EHRs, Dr. Stephen Ross, University of Colorado Health Sciences Center, spoke on the University of Colorado Hospital's experience with patient-accessible EHRs, with a focus on patient education and navigation, and Sam Marafioti, CIO, Sunnybrook Health System, spoke on managing strategies for institutional change. Speakers from the Netherlands, Spain and Iceland also spoke sharing an international perspective on the current state of PAEHRs in their countries.

The workshop alternated between expert presentations that highlighted significant issues to frame the discussions, and break out sessions that were dedicated to exploring each of the four thematic areas in greater detail within the Canadian context. Participants in each group were tasked with developing 6-8 recommendations for the theme of each session. Before the workshop, policy briefs (appendices A-D) that summarized the thematic area, suggested supplemental readings, and presented recommendation samples to assist the discussion were circulated. These policy briefs provided a foundation upon which the recommendations were developed and refined.

#### *Summary of Breakout Discussions*

##### *A. Patient Access to the EHR*

Two general and different approaches for providing patients access to their EHR were discussed. The first approach is to provide individuals access to only the relevant content in their record, preferably tailored to meet their needs, with the necessary educational support to both access and understand the information. The second approach

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<sup>2</sup> In a last minute schedule change Sylvia Klasovic, LLB, Anzen Consulting, presented remarks on behalf of Dr. Yamashita

would be to provide open access to all information contained within an EHR and allow the patient or their delegate to decipher what information they feel to be relevant. Although both views were presented, the general consensus was that providing partial access with tailored educational materials was the preferable, but also a more costly and complex approach for providing patients access to their EHR.

Several specific questions were raised about how and what information in an EHR should be made accessible. One suggestion was to provide only interpretations of the record so that patients do not misinterpret the information. Another suggestion was helping patients manage their care through the record by means of an option for scheduling appointments, obtaining prescription renewals and communicating with health care providers. Most participants agreed that patients should have access to their lab results, but there were varying opinions on how this should be provided (for example, only after being vetted by a physician, or viewed only in the presence of a health care professional). It was also suggested that moving towards PAEHRs is perhaps pushing for something that society is not yet ready for, but the majority of the group responded that access to an EHR is a fundamental patient right, and the movement towards adopting PAEHRs should not be stalled.

Discussion ensued regarding the need for, and role of, education in relation to PAEHRs. The point was made that patients will often need a translation of the content in their EHR, but in earlier surveys on patient preferences regarding access to their record, there was an expressed desire to have access to the authentic, “untranslated” EHRs. Providing access to an EHR will likely result in increased or different types of questions from the patients. Thus human resources will have to be adjusted to meet the patient need. Educational materials embedded in the record could serve as a way of increasing understanding and potentially decreasing anxiety around the content of the record. It was also noted, that the IT system supporting PAEHRs should be flexible enough to adapt to the patient’s literacy and skills.

When deciding on the design of an EHR, an exploration of the ideal relationship between the provider and the patient needs to be undertaken. One suggestion was that providers could be instrumental in designing the base product, and that consumers would then drive the necessary change needed to meet their needs. Others argued that the design of EHRs has little to do with the record itself, or who will be accessing the record, and is primarily about optimizing workflow. The complexity of the language used in EHRs was also discussed. Although professional language/jargon is foreign to most patients, there was agreement that professional language would remain a part of the record to enable communication between different health care providers.

The group also spent time discussing the meaning of “access”. It was agreed that “patient access” should include the ability for patients to make entries into their EHR. Patients should be both receivers and contributors of information. Allowing for patient annotation could increase the patient’s sense of control over the content.

The need for both professional and lay commitment to and support of PAEHRs was articulated. The importance of physician buy-in was stressed, and the need for physician leaders to understand the business value of the PAEHR and then demonstrate the benefits to their colleagues. From the patient’s point of view, it was suggested that if PAEHRs were made more readily available (such as internet banking), people would recognize the need and be more willing to use the service. Prior studies evaluating

provider and patient attitudes towards PAEHRs before and after PAEHR introduction have repeatedly shown that providers are most skeptical before introduction, and that this skepticism disappears or diminishes after successful introduction, as long as there are no noticeable negative side effects such as increased patient demand for services.

Conversely, patients often show a high degree of enthusiasm for the idea of PAEHRs before introduction, but are less enthusiastic after they actually have access to their EHRs. This may be the result of inappropriate implementation (leading to usability problems), limited use of data in the EHR without additional educational information, or a combination of both.

From the discussion and with reference to the draft policy recommendations presented in the policy brief, the following recommendations were drafted:

- 1) A framework needs to be defined whereby all Canadians can have access to at least some elements of their EHR in institutions where such a record exists
- 2) Within a pre-determined time period, all Canadian health care facilities should be responsible for providing high performance care.
  - a. The ability of providing high performance care is dependent on the presence of an EHR and patient-participation.
  - b. Large-scale adoption of EHRs and PAEHRs will be achieved by implementing a business plan, rather than by “imposing” a need for them on institutions.
- 3) Providers and the public should be educated to increase awareness that patient charts (records) and the information contained therein belongs, at least in part, to the patient, and that it can and should be accessed by them.
- 4) The move towards empowering patients by providing them with access to their EHR/patient health record (PHR) and any necessary educational materials should become the standard of care.
- 5) Formal research is necessary in the field of PAEHRs in addition to implementing a change in current practice. The impact of PAEHRs should be studied in order to demonstrate actual effects.

### *B. Privacy and Confidentiality*

The issue of ownership or custodianship of an EHR and its content was widely discussed. It was explained that, from a legal standpoint, ownership does not apply to personal health information, since ownership connotes a material object rather than something as immaterial as information. When discussing health information, it is more appropriate to discuss control. In health care, this can translate into territorialism since many providers are unwilling to give up what has traditionally existed in their domain. A central feature of the provincial laws governing health privacy is recognition of patients' rights to control their information, specifically individual access to one's information. These legislated changes have not been fully accepted in professional practice.

There are, however, aspects of the health record that are more easily understood and accepted as being within the control of the patient. For example, an EHR contains both lab results and an interpretation of those results. It could be argued that the factual results are in the domain of the patient, but the interpretations and the professional opinions reflected are in the domain of the providers. This framework is consistent with the legislative framework, as provincial laws providing access and correction rights to the

patient are not without limitation. Within the provincial laws, there is still room for providers to refuse requests for access where such access could potentially cause harm, or requests for correction where the information in question is a professional opinion made in good faith.

It was argued that as patient access continues to increase, this would ultimately result in a culture shift related to the control of health information. Even if this culture shift occurs, and patients access their EHRs more frequently, it would still be necessary to understand why patients want access to their information, that is, to ensure that appropriate support is provided. It was generally agreed that in most situations patients would only need to access the information that would help them manage their health care.

The presence of delegate and proxy users (e.g. family members or other care providers) raise important issues of security in relation to PAEHRs. Should these individuals be given access to the record? How should they be able to access this information? Among other concerns, there is the issue of how to manage the different people who may legally be able to access the record, but who have dissenting agendas (i.e., multiple family members who have differing views on how to best treat an elderly family member suffering from severe dementia). As PAEHRs become more commonplace, mechanisms will need to be in place to ensure the accuracy, integrity and quality of the record, especially in situations in which patient entries are permitted and incorporated into the record. In addition, policies are required to manage the retention of information.

The emergence of patient portals and the ability to customize patient views creates the additional challenges of defining where the institutionally based EHR ends and the patient portal begins. For example, do patient entries in the portal become part of the EHR? If they do, under what circumstances can this information be accessed, and by whom?

Questions of access to different aspects of an EHR led to a discussion of the “lock box”. The lock box provides patients with the ability to put rules and restrictions on how information flows in or out of the care setting. The question was raised if providers should be permitted to institute lock boxes within a patient chart. This is a concept contemplated as a provider “sealed envelope” in the UK National Health Service Care Record project and could provide a framework for providers seeking to utilize the legal right to refuse the patient’s right of access where there is believed to be a significant risk of harm. If this is permitted, under what circumstances should it be allowed - to prevent harm, only on sensitive content, or to control the timing of the release of information in the context of the limited scope under which providers are permitted by law to refuse access?

From the discussion, and with reference to the draft policy recommendations presented in the policy brief, the following recommendations were drafted:

- 1) Implementation of patient accessible EHRs requires a clear understanding and definition of custodianship/ownership of EHRs.
  - a. An explicit statement of who has custodial authority is required, and it is recommended that control be shared between the patient and the provider in a framework that is respectful of patients’ privacy and autonomy.
- 2) The option of limiting accessibility to certain parts of an EHR should be provided.
  - a. Patients should be able to decide which elements of their EHRs they wish to

- access.
- b. Support should be provided to assist with understanding the content that patients access - at a minimum, this should include interpretation of test results.
- 3) Mechanisms that ensure security and access control and/or management should be put in place.
  - a. Patients should have the ability to delegate access to their own EHR
  - b. Assurances are necessary to ensure that content in an EHR is accurate and complete, and that patients are aware of institutional procedures to challenge the accuracy and completion of the information
  - c. A system of physical, technical and administrative protections or safeguards needs to be in place for both the patient and the institution. These standards should, at a minimum, meet current standards.
  - d. The organization should have protocols for limiting patients' access to their information and a procedure for communicating these restrictions in compliance with relevant legal standards where such standards exist
- 4) Systems of data retention need to be clearly defined.
  - a. A formal system of how the data can be accessed and when it can be accessed needs to be in place.
  - b. For institutions that use both an EHR and a patient-accessible portal/PHR, there needs to be a clear understanding of where the official EHR ends and the portal/PHR starts. There may be different rules and requirements for which elements and for how long these need to be retained by the institution. This framework must be communicated to the patient.
  - c. For institutions that were using an EHR and have added a portal/PHR, current policies on access will need review and revision.

### *C. Patient Education & Navigation*

It was generally agreed that education in relation to an EHR and its navigation were important. It was also recognized that there is a responsibility to follow-up with patients once education is provided to confirm that the patient is able to read, understand, and absorb the information provided. It was not agreed that everyone needed to be exposed to the educational tools. One suggestion was that only consumers who ask for educational support should receive it. A compromise approach would be to embed links to credible educational sites within an EHR so that patients could access that material if and when they need it.

In this case, education can be understood as a means of teaching patients how to better use the data found in their EHR and how to manage their disease. Teaching people about EHRs and its contents is also necessary. Some fear that patients will use these educational resources to replace their doctor. Most commonly, patients want just enough information to understand and make healthy decisions. Providing access to an EHR without educational resources could have some potentially severe side effects, but when those resources are available, it is much more likely to help patients make better decisions about their health.

The tailoring of education was a topic much discussed during the workshop. Questions were raised about the locus of responsibility and if it lay with the provider,

particularly because creating educational material and implementing tailored education is a potentially costly and complex undertaking that may scare providers away from providing access to basic EHR information.

The possibility of creating a National Advisory Board to develop standardized educational content for use in EHRs was also explored. It was suggested that Canada invest in a portfolio of standardized educational materials, which would enhance providers' ability to deliver this type of education, and that educational resources should have some form of standardized rating. Some expressed concern about whether health care providers would be expected to have a standard level of competency in providing patient education.

From the discussion, and with reference to the draft policy recommendations presented in the policy brief, the following recommendations were drafted:

- 1) Access to information in an EHR is more likely to result in better health if it is linked to credible educational and support materials and resources. These can include informational sources for individual learning, or a direct link to an educator or information specialists.
- 2) Providing patients with access to their EHR creates unprecedented opportunities to capture patient experiences and to tailor educational materials to individual patient needs. Health care providers and educators need to capitalize on these opportunities, which may result in improved health related and quality of life outcomes.
- 3) The information that is provided in an EHR should reflect the needs of the target populations and should be culturally and linguistically relevant.
- 4) Educational materials that are linked to an EHR should also be targeted to family members and caregivers where appropriate.
- 5) National standards should be developed to promote the dissemination of EHR-related education materials to facilitate interoperability.
- 6) In addition to the educational materials that are necessary to understand the content of an EHR, a wide scale mechanism should be put in place to enable the public education necessary for patients to access and understand the EHR.
- 7) Research is required to determine the most effective ways to engage patients in the care process, in order to support behavioural change and improved health outcomes.

#### *D. Institutional Strategies for Change*

Health care institutions are faced with the challenge of how to manage change associated with the adoption of new technologies, such as PAEHRs. A major barrier to the adoption of these technologies is a perceived threat to clinical practice. One approach to ensuring successful adoption of these technologies is to help clinicians feel less threatened by the new technology. This could be achieved by demonstrating the benefit of the innovation. Once benefit has been demonstrated and there is supporting evidence, quick acceptance by early adopters can help to influence others in the institution. It is helpful to introduce change in one group at a time, rather than in the entire institution, this allows for the demonstration of successes and easier adoption across the institution.

It was suggested that in order for an institution to be able to better manage the change associated with PAEHRs, there needs to be a firm acknowledgement on the part of the institution that access to medical records is a right. Once this right is

acknowledged at the institutional level, implementing PAEHRs can proceed.

Accepting the cost of change is another step towards successful change-management. Unless institutions are willing to cover the costs associated with the adoption of new technologies, it is unlikely that they will succeed.

Ensuring that workload will not be overly impacted is another key part of effective change management. When implementing new technologies there needs to be the acknowledgement that workloads will increase in the short run. There also needs to be continuous organizational reassurance that the increased burden will not last long, and that support will be provided.

One participant shared his experience with the adoption of a PHR in their institution and stressed the need for a clinical champion. The champion should be someone who is willing to work for the cause even if there is no direct benefit to him/her. The participant shared how he searched his institutions for months to find the right person to champion the cause of adopting the new technology associated with the PHR. In addition to having a champion, it was suggested that the focus not be on the “new product”, but rather on something that all could relate to - example, placing less emphasis on the adoption of EHR/PHR, emphasizing instead how using an EHR/PHR is as easy as navigating a website.

The success of institutional change is also dependent on having the right drivers for change. In an institution committed to patient centred care, for instance, having patients as the drivers of change may help guarantee success.

It was recognized that the healthcare industry is different from other industries. In health care, relationships between “consumers” and “providers” are often characterized by fear and uncertainty because of the knowledge differential that exists between patients (consumers) and providers. Unlike customers in other industries, patients have traditionally been powerless consumers, who lack the influence to demand products (for instance PAEHRs). Now that patients are becoming more empowered, health care systems need to develop means of meeting the consumers’ demands and needs.

From the discussion, and with reference to the draft policy recommendations presented in the policy brief, the following recommendations were drafted:

- 1) Institutions need to be proactive and accelerate the implementation and adoption of PAEHRs. Successful implementation is dependent of the following:
  - a. The creation of structured approaches to change management within organizations to support the development of PAEHRs. These approaches must meet the needs of the end users (including patients), and must be operationalized as a standard for development.
  - b. The development of change management activities to support patient access to an EHR, that include a comprehensive analysis of the cultural climate of the organization and identification of barriers that may prevent the adoption of patient-access to the EHR.
  - c. The development of mechanisms to help organizations manage/overcome barriers to implementation of PAEHRs.
  - d. The development of mechanisms that incorporate long-term sustainability and integration of PAEHRs into the clinical care process.

- e. A national forum should be created for knowledge-sharing regarding how to manage institutional change in relation to the adoption of PAEHRs. (This forum should be included as a component of an e-health summit or conference).
- 2) The successful adoption of new technologies requires embracing a holistic concept of patient-centred care.
    - a. The concept of “patient-centred care” needs to be operationalized and established as a central concept in the delivery of health services. The operationalization should include the right for patients to access the health information contained in their EHR.
    - b. Educational institutions that train health care providers should be encouraged to incorporate patient-centred concepts within their curricula.
- 3) Government
    - a. Government must expedite the e-health agenda as a priority in Canada and expend the required resources to support the development and implementation of interoperable EHRs.
- 4) Patient advocacy
    - a. Establish a grassroots patient movement to mobilize patients’ awareness of their right to access their personalized health information to support self-managed care and decision-making.
    - b. A national statement for patient awareness of rights to access their EHR needs to be developed and adopted as a standard within the delivery of health services.

#### **PART IV – Conclusions**

Canadian health care institutions are contributing to the emergence of EHRs. Although certain areas appear to be leading in this area, approximately 10% of our respondents viewed themselves as leaders in the field of EHR; there are clusters of usage across the country. About half of the respondents to this study believed they were “on track” with respect to EHR uptake and usage. As EHRs become more common, several organizations are beginning to explore the possibility of responding to patient needs for clinical information by providing patient access to EHRs or developing PHRs. It is clear, however, that utilizing these technologies poses several challenges to health organizations. Although many will agree that patients should have access to their health information and associated educational resources, the best way to actualize this is still being debated. Before widespread use of PAEHRs can become a reality or even a standard of care with affiliated practice guidelines, it is paramount that we resolve privacy and confidentiality issues such as ownership rights. Once these and other issues are resolved, there are a number of organizational and research issues that need to be addressed. These challenges should not hinder the movement towards the implementation of PAEHRs, but should instead be viewed as motivators for creating the best possible product to meet all of the stakeholders’ needs.

The opportunity to improve and perhaps even revolutionize the delivery of health care is upon us. As new models of care delivery, such as chronic disease management, become an integral part of the health care system, organizations will have to address issues related to PAHERs in order to optimize their use and maximize their benefit. Now is the time to engage the stakeholder groups required to affect this change. Physicians, nurses, administrators and government, health information specialists, health services researchers, and most importantly, patients must be engaged in the process.

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## Appendix A

### **Policy Brief Patient Access to the Electronic Health Record**

**Speaker:** James Walker  
**Co-Facilitator:** Howard Pai

#### **Introduction:**

The utilization of information technology to facilitate patients' access to their health records can have several potential benefits to patients, health care providers and the healthcare system. Examples of benefits to patients may include more convenient and timely access to health records, the ability to schedule appointments and maintain an electronic diary of their health history. The provision of electronic health records to patients may also facilitate communication between patients and health care providers and engage patients more in their own healthcare. Ultimately, we envision that providing patient access to their electronic health records will be a determinant of health outcome and satisfaction with care.

One necessary condition for bridging technology and patient access is a well-thought out strategy and implementation. Investment in technology cannot take place without first understanding needs, barriers, gaps, process issues, the health delivery system and the information requirements for the future.

#### **Topics of interest and research questions:**

- Peer-reviewed evidence.
  - What does the peer-reviewed evidence demonstrate? What are the benefits and potential harms of patient access to electronic health records?
- Needs assessment.
  - Is there a need for this technology? If so, who will benefit and how?
- Buy-in .
  - Who are the major stakeholders and are they involved? Who will lead this initiative?
- Patient empowerment – Will the patient armed with access to their own health records, coupled with credible health information tailored to their needs, become a more active partner in the health care encounter?
  - What will this mean for treatment decision-making?
  - Is the health care system ready to support empowered patients?
  - What mechanisms need to be in place to provide and support patients access to their health records?
- An empowered patient will necessarily result in changes to the patient-physician relationship.
  - What type of professional support is necessary to support physicians and

- other healthcare providers in communicating with the “new empowered patient”?
- Information technology will enable patients in remote areas to more easily integrate into larger health care systems.
    - Does access to one’s own health care information facilitate communication with experts that may not be local?
    - Can Telehealth support having the patient at the centre of the care team in either the role of decision maker and/or gatekeeper of information?
  - Providing patients with access to their health record may result in improved information sharing capabilities among different levels of healthcare personnel and patients.
    - What mechanisms need to be in place to ensure that the patient shares the appropriate and accurate information with each health care provider?
    - Who should have access to the EHR? And how will this be regulated?
    - Should access be provided to the full record, or only relevant sections of the EHR?
  - Convincing consumers and providers to change old habits and to adopt using information technologies to access health care information.
    - How and when do we make patient accessible records the standard of care?
    - Who is going to pay for it: consumers, government, health care providers, and/or private industry partnership?

### **Supporting Papers:**

Cimino, J. J., V. L. Patel, et al. (2001). "What do patients do with access to their medical records?" Medinfo **10**(Pt 2): 1440-4.

Anonymous (2004). "Patients accessing Web-based medical records." Internet Healthcare Strategies **6**(6): 1-4.

Pyper, C., J. Amery, et al. (2004). "Patients' experiences when accessing their on-line electronic patient records in primary care." British Journal of General Practice **54**(498): 38-43.

Masys, D., D. Baker, et al. (2002). "Giving patients access to their medical records via the internet: the PCASSO experience." Journal of the American Medical Informatics Association **9**(2): 181-91.

Ross, S., C.T. Lin, (2003). “A randomized controlled trial of patient-accessible electronic medical record.” AMIA . . . Annual Symposium Proceedings/AMIA Symposium 990

Ross, S., C.T. Lin, (2003). “The effects of promoting patient access to medical records: a review.” Journal of the American Medical Informatics Association **10**(2): p. 129-38.

**Policy Recommendations:**

- Within a defined framework all Canadians should have access to their electronic health record in institutions where such a record exists if desired.
- Within a pre-determined time period all Canadian health care facilities should use a basic electronic health record.
- Professional retraining and training of health care professionals to educate providers and patients on accepting that the patient chart and information within belongs to patients and that it can and should be accessed by them (similar to banking or credit card information).
- The move towards empowering patients by providing access to personal health records coupled with the necessary educational materials should become the standard of care.
- (Formal research in this field is needed in addition to implementing a change. We should study the effect of this change to demonstrate true benefit and effect).

## Appendix B

### **Policy Brief Maintaining Privacy and Confidentiality**

**Speaker:** Miyo Yamashita  
**Co-Facilitator:** Tiffany Jay

#### **General Summary:**

Many industries have implemented safe, non-compromising online platforms to relay and exchange consumer information with the support of their clients. These efforts have created a framework in which to consider security when moving forward with patient access to the electronic health record (EHR). However, reflecting the high sensitivity of personal health information, privacy and security remains critical consideration in moving towards this goal. Balancing the security concerns is the movement by legislators to provide patients a statutory right to access their personal health information.

Since the implementation of the HIPAA Privacy Rule in the US, access complaints represented the third most common type received by the oversight body. Many of these complaints related to high cost for access and rigid restrictions on access time and place imposed by providers. Electronic access may provide an avenue to alleviate these concerns. However the other volume of concerns relate to denial by providers of access to all or parts of the patient's record. In addition, providers have reported a reluctance to include sensitive or controversial information in their documentation for fear that patients may complain or demand that information be changed.

Several provinces across Canada have similarly accorded a statutory right for patients to see their health information. These statutes provide limited opportunities for the health provider to refuse the patient's right of access, for example where it is believed that access may cause harm to the patient or another individual. Providers are typically required to make reasonable efforts to make the information accessed understandable to the patient (i.e. provide explanation of acronyms or medical terminology).

Other rights and obligations with implications for electronic patient access include records retention mandates, the need to put into place appropriate safeguards (including security) and requirements for information to be accurate and complete permitting the patient to request correction when this standard is not met.

#### **Topics of interest:**

- Who should develop operational privacy standards for patient access? Institution? Province? Federal?
- Risk of harm – Is there information to which patient shouldn't have immediate access?

- Access Provisioning - Should patients be permitted to delegate access to their record (friends, family)?
- Accuracy & Requests for correction – How do institutions manage concerns brought forward by patients? What effect will patient access have on the record-keeping behaviour of care providers?
- Usability – What is the institutions responsibility for making the information presented meaningful and understandable?
- Storage & Retention – Where should information be retained? For how long? How does patient-generated information relate to the medical record including legal and regulatory standards?
- Safeguards – What security systems need to be in place before an institution can provide patients electronic access to the records? What’s the appropriate balance between the obligations of the hospital and the autonomy of the patient?
- Limiting Use & Disclosure – Should limits be considered around how information collected in the course of providing patient access will be used (e.g. research use of identifiable utilization data or journal entries)?
- Challenging Compliance - What recommendations need to be in place for situations in which confidentiality is breached?

### **Supporting Papers:**

Brown, Bob (2006) “The Patient Access and Request for Amendments Provisions of the HIPAA Privacy Rule.” Journal of Health Care Compliance **8**(3): 37-79.

Hassol, A., Walker, J., Kidder, D., et al. (2004) “Patient Experience and Attitudes about Access to a Patient Electronic Health Care Record and Linked Web Messaging.” Journal of the American Medical Informatics Association **11**(6): 505-513.

Kimber, Tim (2006) “HOW TO... Manage Access to Patient Notes” General Practitioner 6/9/2006: 45.

Masys, D., Baker, D., Butros, A. Cowles, K. (2002) “Giving Patient Access to Their Medical Records via the Internet: The PCASSO Experience.” Journal of the American Medical Informatics Association **9**(2): 181-191.

Tjoral, A., Tran, T. & Faxvaal, A. (2005). “Privacy vs. Usability: A Qualitative Exploration of Patients' Experiences With Secure Internet Communication With Their General Practitioner.” Journal of Medical Internet Research **7**(2): e5.

### **Policy Recommendations:**

- At minimum, each institution wanting to adopt the use of an EHR must adhere to all provincial standards, or where the portal crosses provincial boundaries, to the highest relevant jurisdictional standard.
- Procedures should be in place to respond to questions and requests for correction about the accuracy of the record and support care providers in responding to

- challenges regarding accuracy.
- Security safeguards must be given priority in balance with the need to provide a usable system.
  - In determining what information is accessible, institutions must engage in clinical consultation to ensure that the risk of harm is mitigated when providing access.
    - This may include setting standards around appropriate delays before posting information to a patient portal to provide the provider an opportunity to review results.
  - Education & support are key success component in providing patient access - information provided should be understandable and meaningful.

## Appendix C

### **Policy Brief**

### **Patient Education and Navigation of the Electronic Health Record**

**Speaker:** Steve Ross

**Co-Facilitator:** Audrey Friedman

#### **General Summary:**

Providing patients with access to and involvement with the electronic health record (EHR) is, from a technical point of view, relatively straightforward. However, as the scope of the EHR expands from a clinical management tool to a patient resource and self-management tool the complexities and difficulties quickly arise. If the access is designed to engage and empower patients to participate in their care and better navigate the health system, then perhaps access to clinical data is not in fact sufficient. Further information and education is required to empower patients to participate in their care and better navigate the health system.

There are several potential benefits to be achieved through educating patients on and through the EHR. The benefits include increased patient engagement, satisfaction with their care and overall quality of life. It also provides a platform for web-based interventions to promote patient activation through education around issues of chronic disease management, including adherence to care plans, self-management and self-care strategies. In addition, it has the potential to increase patient safety through awareness and improve patient-provider communications.

From a clinical practice perspective, there are also a number of important benefits to be realized. Clinical management benefits may include a reduction in clinical visits, reduced phone calls to the clinic, reduced wait times, increased patient safety, and improved community integration and outreach. In addition, training and education will play a significant role in the development of patient information systems due to the fact that most patients do not have a sense of what comprises their health record let alone the value of the information contained therein.

Consequently, if we advocate that patients must be more pro-active in their health management and we propose that they access an information system containing their EHR, then we must ensure that patients receive the education they need to best navigate the EHR. Some research has been conducted to demonstrate the importance of targeting and tailoring health messages and the EHR has been identified as a powerful platform that could be harnessed for this purpose. However, there are many clinical, legal, security, educational and social issues which need to be resolved and further research is required to assess impact on clinical practice.

### Topics of interest:

- Training and education for patients and healthcare providers.
  - What levels of education are required to ensure success adoption of accessible EHRs?
  - Should education be optional and sought out by users or mandated and enforced by professional organization, or prescribed by health care providers?
- Tailored vs. Targeted Information.
  - Is information tailored for an individual patient required?
  - How should information be tailored in the context of co-morbidities?
  - Should information be tailored for cultural and linguistic diversity?
  - What are the liabilities connected with tailored information?
- Maintaining content.
  - What systems need to be in place to ensure that educational content is up to date and accurate?
- Patient anxiety - having records available may cause patients to overreact.
  - What systems need to be in place to ensure that people understand the content of their record?
  - How to ensure that support mechanism are in place to support people who read potentially upsetting information in their record?
- What impact will access to records have on current workloads?
  - Additional studies are necessary to determine the impact on the timing of the provider-patient encounter.

### Supporting Papers:

Kane, R. J. (2002). "Information is the key to patient empowerment." Annals of Health Law **11**: 25-44.

Deber, R. B., N. Kraetschmer, et al. (1996). "What role do patients wish to play in treatment decision making?" Archives of Internal Medicine **156**(13): 1414-20.

Fowles, J. B., A. C. Kind, et al. (2004). "Patients' interest in reading their medical record: relation with clinical and sociodemographic characteristics and patients' approach to health care." Archives of Internal Medicine **164**(7): 793-800.

Goldberg, H. I., J. D. Ralston, et al. (2003). "Using an Internet comanagement module to improve the quality of chronic disease care." Joint Commission Journal on Quality & Safety **29**(9): 443-51.

Kreuter, M. and C. Skinner, *Tailoring: what's in a name?* Health Education Research, 2000. **15**(1): p. 1-4.

Kreuter, M. and C. Skinner, *Tailoring: what's in a name?* Health Education Research, 2000. **15**(1): p. 1-4.

Kreuter, M., et al., *Achieving cultural appropriateness in health promotion programs: targeted and tailored approaches.* Health Education & Behavior, 2003. **30**(2): p. 133-46.

Kreuter, M., V.J. Strecher, and B. Glassman, *One size does not fit all: the case for*

*tailoring print materials*. Ann Behav Med, 1999. **21**(4): p. 276-83.

**Policy Recommendations:**

- Patients receiving access to their EHR should also receive access to educational material that will help them understand the elements of their record and any actions they might need to take. These actions may include adhering to care plans, self-management strategies, required follow ups, and additional information and support that could be accessed if required.
- Where possible information should be tailored for patient sub-groups and tailored for the individual clinical needs of patients. Tailoring should be based on clinical parameters and contextualized for patient issues.
- The information that is provided should reflect the needs of the target populations and should be culturally and linguistically relevant.
- The development of National Advisory Boards to develop standardized education content for use in the EHR. The standards should be linked with evidence-based guidelines developed by organizations. Development of standards (guidelines) on healthy living, disease management etc. to be used in conjunction with the EHR
- Funding mechanism in place to enable education necessary around access and understanding the EHR.
- Educational materials should also be targeted to family members and caregivers when appropriate.

## Appendix D

### **Policy Brief Institutional Strategies for Change**

**Speaker:** Sam Marafioti  
**Co-Facilitator:** Claudette DeLenardo

#### **General Summary:**

The implementation of an electronic health record system requires significant organizational change from constituents from all levels; consumers/patients, health care providers and administrators share a common vision. Change is hard. Change is about loss. It disrupts the normal functioning and practices of an organization. In order to support change in practice, the change must be perceived as an organizational priority. The ability to promote change through an organization is dependent on decisions made by members of the system. People will adopt change if they believe that it will be a benefit to them. The implementation of an electronic health record poses one of the greatest changes to one's health care career. In order to ensure successful implementation and adoption, one must affect the attitudes of those individuals who are seen as "leaders" within systems and subsystems. The need to focus on people's willingness to accept change cannot be overstated.

Traditionally, health care providers view the health record as owned by an organization. With the implementation of PHIPA, this traditional way of thinking is being challenged. As a result, organizations must be responsive to changes that support patient access to their health information in a timely fashion. Patient access to the electronic health record to support engagement in self-care management adds another level of complexity to the health care system. Barriers to access include usability, navigation, health literacy and applicability.

#### **Topics of interest:**

- How do we bridge the communication gap between stakeholders (technology consultants, health care providers and consumers (patients)) involved in the development of technology applications for healthcare?
- What change management processes incorporate adoption and long-term sustainability of innovations?
- If patients are engaged in decision-making using technology applications how does it affect the patient-provider relationship? What is the result of this relational change on providers and their perceptions of "patient engagement"? How does this change affect roles within health care?
- How do we engage patients in care using the electronic health record in order to change the context of patient-provider relationship?
- How are patient-centric environments defined?

- Reduction in Canadian health care costs

### **Supporting Papers:**

Clement, M. J. (1997). "The Barriers to Electronic Medical Record Systems and How to Overcome Them." Journal of the American Medical Informatics Association 4: 213-221.

Hassol, A., Walker, J.M., Kidder, D., Rokita, K., Young, D., et al. (2004). "Patient experiences and attitudes about access to a patient electronic health care record and linked web messaging." Journal of the American Medical Informatics Association 11(6), 505-513

Mandel, J. L. e. a. (1998). "Electronic Patient-Physician Communication Problems and Promise." Annals of Internal Medicine 6: 495.

### **Policy Recommendations:**

- Need for research to develop applications that meet the navigation and usability needs of patients.
- Availability of fiscal and human resources for development, implementation and evaluation of change management processes
- Need for research to promote best practices for change management processes.
- Change practices are required to be embedded in the practices of the organization and supported by the management team, senior executive and board of directors.

## Appendix E

### **PAEHR Survey Introduction Letter to Participants**

**Vous trouverez plus bas la version française de cette lettre.**

The Patient Access to the EHR Working Group is conducting a survey on the status of patient access to electronic health records across Canada, supported by the Canadian Institutes for Health Research (CIHR) and Canada Health Infoway (CHI).

An electronic health record is a computerized record of a person's health and/or medical history. This record may contain a person's full health and medical record, or can be used for certain records, such as lab results, in conjunction with a more traditional paper-based patient chart. For the purpose of this survey we are interested in any configuration of electronic patient information that can be called an electronic health record.

Having access to one's electronic health record can empower people to become active participants in their own care, result in better medical management, lead to more effective provider-patient communication and may improve patient satisfaction and improve clinical outcomes. Although there are a few organizations in the US and UK with expertise in this area, no strategies, policies or procedures exist in Canada for providing patients with access to their electronic health record. Results of this survey will provide a starting point for developing these strategies and policies tailored to our needs within the Canadian health care context.

**We would appreciate it if you could assist us by completing this short web-based survey on issues related to patient access to the electronic health record.** If we have contacted you incorrectly, can you please forward this email on to the most appropriate individual at your institution? In addition, please forward this email to the following individuals in your organization: Chief of Medicine, Chief of Nursing, and Head of Medical Informatics so that we can obtain multiple perspectives from your organization.

The survey is anonymous and, although the name of your institution is requested, this is only for administrative purposes and no individual institutional data will be published. Survey data will be analyzed in an aggregate fashion to ensure anonymity of your institution. The web-based survey site is a secure site and any identifying institutional data will be securely kept. Your participation is completely voluntary; you can withdraw from the study at any time. Consent to participate is assumed by completing the survey.

If you have any questions, please contact the research team, at [David.Neligan@uhn.on.ca](mailto:David.Neligan@uhn.on.ca)

**To go to the English survey please click below:**

*<http://www.questionpro.com/akira/TakeSurvey?id=475581>*

Many thanks for your participation.

Yours sincerely,

David Wiljer

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Avec l'appui des Instituts de recherche en santé du Canada (IRSC) et de Inforoute Santé du Canada (ISC), le groupe de travail sur la consultation par les patients du DSE réalise une enquête sur la situation canadienne en ce qui concerne la consultation par les patients des dossiers de santé électroniques.

Un dossier de santé électronique est un dossier informatisé sur la santé ou l'anamnèse médicale d'un patient. Ce dossier peut contenir le dossier santé et médical complet d'une personne ou ne s'utiliser que pour certaines données, comme les résultats des épreuves de laboratoire, conjointement avec un dossier papier traditionnel. Dans le cadre de cette enquête, nous nous intéressons à toute configuration électronique d'information sur le patient qu'il est possible d'appeler dossier de santé électronique.

En permettant aux patients de consulter leur dossier de santé électronique, on peut leur donner le pouvoir de participer de manière active à leurs soins, ce qui entraîne une meilleure prise en charge médicale, améliore la communication entre le prestataire et le patient et, dans certains cas, augmente la satisfaction du patient et améliore les résultats cliniques. Bien que quelques établissements des États-Unis et du Royaume-Uni fassent preuve d'une expertise dans ce domaine, il n'existe pas encore de stratégies, de politiques ou de procédures au Canada pour permettre aux patients de consulter leur dossier de santé électronique. Les résultats de cette enquête serviront de point de départ pour développer ces stratégies et ses politiques, afin qu'elles répondent à nos besoins dans le contexte des soins de santé au Canada.

**Nous vous serions reconnaissants si vous pouviez nous aider en répondant à cette courte enquête en ligne portant sur les questions associées à la consultation par le patient de son dossier de santé électronique.** Si nous vous avons contacté par erreur, pourriez-vous faire suivre ce courrier électronique vers la personne de votre établissement la plus appropriée? Veuillez également faire suivre ce courrier électronique au chef du service de médecine, au chef du service des soins infirmiers et au directeur du service d'informatique hospitalière de votre établissement, pour que nous ayons plusieurs perspectives de votre établissement.

L'enquête est anonyme et, bien que le nom de votre établissement soit nécessaire, ce n'est que pour des raisons administratives et aucun nom d'établissement ne sera publié. Pour s'assurer du caractère anonyme de votre établissement, les données de l'enquête seront regroupées avant d'être analysées. Le site de l'enquête en ligne est sécuritaire et toute donnée permettant d'identifier votre établissement sera gardée en lieu sûr. Votre participation est entièrement volontaire; vous pouvez vous désister de l'enquête à tout moment. Le fait de compléter l'enquête implique que vous consentez à y participer.

Si vous avez des questions, veuillez contacter l'équipe de recherche à l'adresse [David.Neligan@uhn.on.ca](mailto:David.Neligan@uhn.on.ca)

**Pour voir l'enquête en français, veuillez cliquer sur le lien ci-dessous :**

<http://www.questionpro.com/akira/TakeSurvey?id=480982>

Merci de votre participation.

Très sincèrement,

**David Wiljer**

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Appendix F:

CCPAEHR Survey (English)

Section I: Paper Based Patient Record

The following questions relate to providing patients with access to their paper based health and medical records.

Does your hospital use a paper based patient record?

- .  Yes  No

Are patients permitted to access their paper record?

- .  Yes  No

What is the procedure a patient must follow in order to gain access to his/her paper based record?

- .  Request a copy from treating physician  
 .  Request a copy from the medical records department/Health Information

Management department

- .  Submit a formal written request to hospital administration  
 Other

When patients request access to their paper based record how long does it take to fill the request?

- .  Immediately  
 .  Less than one day  
 .  Between 1 – 3 days  
 .  Between 4 –7 days  
 .  Longer than one week  
 Other \_\_\_\_\_

Are patients charged a fee when they request access to their paper based record?

- .  Yes

- .  No

How much does it cost?

- .  \_\_\_\_\_

When patients request access to their paper based record how is the record presented?

- .  Full record
- .  Summaries only
- .  Requested sections only
- .  Other \_\_\_\_\_

On average, how many patients request access to their paper based record each month?

- .  1 – 5
- .  5 – 20
- .  20 – 50
- .  50 – 100
- .  more than 100

Are family members permitted to access the paper record?

- .  Yes
- .  No

What is the procedure a family member must follow to access the paper record?

- .  With written consent from patient
  - .  Acting as the patient's guardian
  - .  Acting with a Power of Attorney
  - .  Other (describe)
- 

## Section II: The Electronic Health Record

Does your hospital have an electronic health record/electronic medical record/electronic patient record (EHR)?

- .  Yes
- .  No

When did your institution adopt the use of an EHR?

- .  Within the last 3 months
- .  Within the last 6 months

- .  With in the last 12 months
- .  More than one year ago
- .  More than 5 years ago
- .  More than 10 years ago

Where does the funding come from to support the use of the EHR?

- .  Your institution
- .  Private Industry
- .  Research Grants
- .  Donations
- .  Provincial funds
- .  National funds

Is the EHR the only method for recording patient information?

- .  Yes
- .  No

What percentage of the patient record is electronic?

- .  0 - 10%
- .  11 – 50%
- .  51 – 90%
- .  91 – 100%

Does your institution use an “off the shelf” EHR product?

- .  Yes
- .  No

Which of the following describes your EHR? (select all that apply)

- .  Customized off the shelf product
- .  Built in-house
- .  Outsourced
- .  Design input from clinicians
- .  Design input from patients
- .  Collaborative project between several organizations
- .  Reflects format/design of paper chart

Who can make entries into the EHR?

- .  Physicians
- .  Nurses
- .  Allied health care professionals
- .  Chaplains
- .  Administrative personnel

- .  Support staff
- .  Community physicians
- .  Patients
- .  Family members
- .  Other \_\_\_\_\_

We are interested in learning about ownership of and access to the EHR.

In your hospital who is identified as the official owner of the EHR?

- .  Hospital
- .  Health care system
- .  Health care provider
- .  Patient
- .  Other \_\_\_\_\_

In your hospital who is permitted to access the EHR without special authorization?  
(Select all that apply)

- .  Physicians
- .  Nurses
- .  Allied health care professionals
- .  Chaplains
- .  Administrative personnel
- .  Support staff
- .  Community physicians
- .  Patients
- .  Family members
- .  Other \_\_\_\_\_

What is the procedure a patient must follow in order to gain access to his/her EHR?

- .  Request access from the treating physician
  - .  Request access from the medical records department/Health Information  
Management department
  - .  Submit a formal written request to hospital administration
  - .  Other \_\_\_\_\_
-

In order to access the EHR online are there any other procedures that patients must follow (select all that apply)?

- Obtain a password
- Provide official consent
- Complete training
- None
- Other \_\_\_\_\_

What is the average yearly cost of providing patients with access to their EHR? (List in Canadian Dollars)

- \_\_\_\_\_

On average, how many patients request access to their EHR each month?

- 1 – 5
- 5 – 20
- 20 – 50
- 50 – 100
- More than 100

The following questions pertain to policies related to the EHR.

Is it a written institutional policy that all patient information be record in the EHR?

- Yes
- No

Would you be willing to provide a copy of the policy?

- Yes
- No

Please mail or email a copy of the policy to: Dr. Sara Urowitz, Research Associate and Postdoctoral Fellow, Oncology Education and Survivorship, University Health Network Princess Margaret Hospital 14-411610 University Ave. Toronto, ON M5G 2M9 [sara.urowitz@uhn.on.ca](mailto:sara.urowitz@uhn.on.ca)

Does your hospital have a written policy on providing patients with access to the EHR?

- .  Yes
- .  No

Would you be willing to provide us with a copy of the policy?

- .  Yes
- .  No

Please mail or email a copy of the policy to: Dr. Sara Urowitz, Research Associate and Postdoctoral Fellow, Oncology Education and Survivorship, University Health Network Princess Margaret Hospital 14-411610 University Ave. Toronto, ON M5G 2M9 [sara.urowitz@uhn.on.ca](mailto:sara.urowitz@uhn.on.ca)

Does your hospital have an informal policy on providing patients with access to the EHR?

- .  Yes
- .  No

Please describe

\_\_\_\_\_

Does your hospital have a policy on maintaining confidentiality of the EHR?

- .  Yes
- .  No

Would you be willing to provide us with a copy of the policy?

- .  Yes
- .  No

Please mail or email a copy of the policy to: Dr. Sara Urowitz, Research Associate and Postdoctoral Fellow, Oncology Education and Survivorship, University Health Network, Princess Margaret Hospital 14-411610 University Ave. Toronto, ON M5G 2M9 [sara.urowitz@uhn.on.ca](mailto:sara.urowitz@uhn.on.ca)

What do you perceive are the key factors in driving faster adoption of EHR solutions?

	Least Important		Somewhat Important		Most Important
Consumer demand					
Provider demand					
Executive leadership					
Access to funding					
Access to better information					
Other					

Please describe any Other key factors What do you perceive are the key barriers in developing or implementing an EHR?

\_\_\_\_\_

Least Important

Somewhat Important

Most Important

Cost

Privacy concerns

Coordination of multiple stakeholders across continuum of care (e.g. governance)

Education and training about EHR

Time and effort required to develop or implement

Other

Please describe any other barriers

\_\_\_\_\_

There are several key benefits for providing an EHR. In order of priority what do you perceive are the key benefits an EHR provides?

	Least Important		Somewhat Important		Most Important
Patient safety					
Clinical workflow efficiencies					
Quality of care					
Continuity of care					
Other					

Please describe any Other benefits

\_\_\_\_\_

With respect to other EHR initiatives in Canada, where do you think your organization ranks?

- .  Lagging Behind
- .  On Track With Others
- .  Leader

### Section III: The Information Technology Infrastructure

We are interested in learning about your institution’s current information technology (IT) infrastructure and its ability for supporting access to the EHR. (Please answer to the best of your ability even if no EHR is used.)

Does your current IT infrastructure support the use of an EHR?

- .  Yes
- .  No

Does your current IT infrastructure support patient access to the EHR?

- .  Yes
- .  No

Are there plans for implementing appropriate IT infrastructure?

- .  Yes
- .  No

Please explain why not. Please describe

\_\_\_\_\_

From which locations can patients access their EHR?

- .  Hospital computer
- .  Any computer with an Internet connection
- .  Other \_\_\_\_\_

Do your patients access the EHR through the Internet?

- .  Yes
- .  No

Is there a mechanism in place to permit several different individuals, using unique passwords, to login to a single chart (e.g., to permit patients' family members to access the EHR)

- .  Yes
- .  No

#### Section IV: Perceptions about providing access to the EHR

The following questions are intended to help us understand staff perceptions about the use of the EHR.

Has your hospital conducted any formal survey of staff perceptions around providing patients with access to the EHR?

- .  Yes
- .  No

Would you be willing to provide us with a summary of your findings?

- .  Yes
- .  No

Please mail or email a summary of your findings to: Dr. Sara Urowitz, Research Associate and Postdoctoral Fellow, Oncology Education and Survivorship, University Health Network Princess Margaret Hospital 14-411610 University Ave. Toronto, ON M5G 2M9 [sara.urowitz@uhn.on.ca](mailto:sara.urowitz@uhn.on.ca)

In your opinion what are the perceptions of staff regarding providing patients with access to the EHR?

- .  Open and willing
- .  Hesitant but willing
- .  Willing to provide partial access
- .  Other \_\_\_\_\_

Which elements of the EHR are staff most willing to provide patients with access to?

- .  The full record
- .  Notes
- .  Test results
- .  Diagnostic Reports
- .  Pathology reports
- .  Other \_\_\_\_\_

The following questions are intended to help us understand patient perceptions about the use of the EHR.

Has your hospital conducted any formal survey of patient perceptions around accessing the EHR?

- .  Yes
- .  No

Would you be willing to provide us with a summary of your findings?

- .  Yes
- .  No

Please mail or email a summary of your findings to: Dr. Sara Urowitz, Research Associate and Postdoctoral Fellow, Oncology Education and Survivorship, University Health Network Princess Margaret Hospital 14-411610 University Ave. Toronto, ON M5G 2M9 [sara.urowitz@uhn.on.ca](mailto:sara.urowitz@uhn.on.ca)

In your opinion what are the perceptions of patients regarding accessing the EHR?

- .  Eager
- .  Hesitant but willing
- .  Desire only partial access
- .  Other \_\_\_\_\_

Which elements of the EHR are patients most interested in accessing?

- .  The full record
- .  Notes
- .  Test results
- .  Diagnostic reports
- .  Pathology reports
- .  Other \_\_\_\_\_

Is your hospital management supportive of providing patients with access to the EHR?

- .  Not Very Supportive
- .  Moderately Supportive
- .  Very Supportive

Does your hospital have a champion or steering committee for providing patients with access to the EHR?

- .  Yes
- .  No
- .  Not Sure

Please describe

- \_\_\_\_\_

There are several barriers that have been identified to effectively giving patients access to the EHR. How important are the following barriers in your hospital?

	Not very important		Moderately important		Very important
Hospital financial resources					
Clinician buy-in					
Patients' access to computers					
Patients' computer literacy					

Placing a high value on embracing change has been identified as a necessary element of providing patients with access to the EHR. How well does your institution manage change?

- .  Not Very Readily
- .  Moderately
- .  Very Readily

It has been suggested that providing patients with access to their EHR should be coupled with aides to better help people understand and cope with the information in the record. The following questions are interested in what type of patient support is provided to individuals who access the EHR?

Does your hospital provide disease-specific education materials?

- .  Yes
- .  No

Does your hospital provide general education materials as part of the electronic health record?

- .  Yes
- .  No

Does your hospital provide patient education materials specifically designed to help patients understand their EHR?

- .  Yes
- .  No

## Section V: Demographics and Institutional Information

Please indicate your title/position

- .  Chief Executive Officer
- .  Chief Information Officer
- .  Chief of Medicine
- .  Chief of Nursing
- .  Other \_\_\_\_\_

What is the name of your hospital?

- \_\_\_\_\_

Is your hospital part of a health care system/larger institution?

- .  Yes
- .  No

What is the name of the health care system/larger institution?

- \_\_\_\_\_

Where is your hospital/health care system/larger institution located?

- .  Alberta
- .  British Columbia
- .  Manitoba
- .  New Brunswick
- .  Newfoundland and Labrador
- .  Northwest Territories
- .  Nova Scotia
- .  Nunavut
- .  Ontario
- .  Prince Edward Island
- .  Quebec
- .  Saskatchewan
- .  Yukon

How many beds does your hospital have?

- .  Less than 100
- .  100 to 400
- .  More than 400

Appendix H  
Workshop Attendees – Oct 19, 2006

Attendee Name	Affiliation
James Walker	Geisinger Health System
Howard Pai	Co-Facilitator – British Columbia Cancer Agency
Miyo Yamashita	Anzen Consulting
Tiffany Jay	Co-Facilitator – University Health Network
Steven Ross	University of Colorado
Audrey Friedman	Co-Facilitator – Princess Margaret Hospital
Sam Marafioti	Toronto Sunnybrook Regional Cancer Centre
Claudette DeLenardo	Co-Facilitator – Grand River Hospital
Kevin Leonard	University Health Network
Margo Brown	Canada Health Infoway
Sarah Muttitt	Canada Health Infoway
Gyao Halldorsdottir	Iceland
Nicolas Garcia Gonzalez	Clinica Universitaria de Navarra
J.W. (Hans) van der Slikke	VU University Medical Center
Todie Winter	Princess Margaret Hospital
Emma Apatu	Princess Margaret Hospital
Andrea Chiarmida	Princess Margaret Hospital
Elyse Chan	Princess Margaret Hospital
Michelle Arbuckle	Princess Margaret Hospital
Carol-Anne Sullivan	Princess Margaret Hospital
Robert Luke	Princess Margaret Hospital
Pam Catton	Princess Margaret Hospital
Mary Gospodarowicz	Princess Margaret Hospital
Sara Urowitz	Princess Margaret Hospital
Tamara Harth	Toronto Sunnybrook Regional Cancer Centre
Warren Winkelman	Health Care, Technology & Place Faculty of Nursing U of T
Joanne Hohenadel	University Health Network
Wayne Evans	University Health Network
Selina Brudnicki	University Health Network
Laura Macaulay	University Health Network
Mark Casselman	University Health Network/SIMS Partnership
Christine Marton	Tom Baker Cancer Centre Library
Peter Pennefather	University of Toronto
Carlo DeAngelis	Sunnybrook & Women's College Health Sciences Centre
Joe Cafazzo	University Health Network
Yvette Matyas	Toronto Sunnybrook Regional Cancer Centre
Amy Caison	Memorial University of Newfoundland
Roxana Sultan	Cancer Care Ontario
Lucy McDonald	Centre for Health Information
Gena Piliotis	Sunnybrook Health Sciences Centre
Amy Melnick	Sunnybrook Health Sciences Centre
Sarina Giraldi	Sunnybrook Health Sciences Centre
Kui Chun Su	Warren General Hospital
Gunther Eysenbach	University Health Network – Toronto General Hospital
Derek Ritz	ECCGroup Inc.