

A PAN-CANADIAN ELECTRONIC HEALTH RECORD SYSTEM:
PRIVACY IMPLICATIONS FOR THE ELDERLY AND CHRONICALLY ILL

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A Research Paper submitted to the Graduate Program in Health in partial fulfilment
of the requirements for the degree of

Master of Arts

Graduate Program in Health
York University
Toronto, Ontario
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July 2012

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Preface

The statements and assumptions made within this paper are contingent on my identity and position within society. I am a graduate student in the Health Policy and Equity program at York University. In my undergraduate studies at the University of Toronto, I majored in Psychology and minored in English Literature and Fine Art History. In addition to my role as a student, I have been employed at the Nurse Resource Team at the Veteran's Care facility within Sunnybrook Health Sciences Centre since November of 2010. Thus, my research interests have been fuelled by my firsthand experience with issues of privacy for elderly citizens living with chronic illnesses.

Introduction

Problem Statement

Elderly citizens who suffer from chronic conditions are a vulnerable group within Canada, due to their distinct needs and characteristics. According to the Canadian Institute for Health Information (2011), nearly half of Canadian seniors report suffering from one to two chronic conditions, while nearly a quarter (24%) report more than three chronic conditions. Seniors with three or more chronic illnesses have three times more health care utilization than seniors without chronic conditions. Following the guidelines put forth by Canada Health Infoway, the Province of Ontario has committed to implementing a comprehensive electronic health record (EHR) system by 2015. Although proponents of electronic health records claim that they can promote coordinated and efficient patient care, it is necessary to explore the privacy implications of EHRs and inclusion of diverse perspectives to enable effective health policies. Thus, it is important to consider the privacy implications of Ontario's Personal Health Information Protection Act (PHIPA). Through the use of a scoping review, this paper will examine whether EHRs can adequately protect the privacy of chronically ill seniors in relation to PHIPA, or whether alternative measures need to be implemented. Furthermore, it will be determined which political and commercial actors are involved within EHR implementation and whether the concerns of chronically ill and elderly populations will be adequately presented. Subsequently, recommendations will be proposed for how the stated issues can be addressed, in order to protect the privacy of elderly persons suffering from chronic illnesses.

Seniors in Canada

Aging is a natural phenomenon and seniors are important members of society. Over the last few decades, two issues have become prominent for seniors on a global basis: longevity and chronic illnesses.

Changing demographics.

As the number of senior citizens within Canada continues to steadily rise, so is the prevalence of chronic conditions. Canada's median age has gone up dramatically in the last century. According to Statistics Canada (2011), in 2001, the median age of Canada's population was 37.2 years. However, as of July 1st, 2011, the median age of Canada's population was estimated at 39.9 years. According to Health Canada, given current population trends, 15.9% of Canadians or 5.9 million individuals will be senior citizens by the year 2016. As a result, by 2040, more than 20% of Canadians will be considered senior citizens (Snowdon et al., 2011). According to the Canadian Institute for Health Information (2011), in addition to overarching population trends, health care utilization patterns reveal that healthy seniors require less health care. More specifically, the amount of health care services that senior citizens utilize is largely dependent on the number of chronic conditions that they suffer from, rather than their age.

Chronic illnesses.

A chronic illness is defined as a life-long illness or disease that has long-term health management implications (Leonard & Dalziel, 2011; Leonard, Casselman, & Wiljer, 2008). Individuals who suffer from chronic conditions are typically on long-term medication and/or treatment regimens, and the treatment often involves their family

physician or general practitioner, in addition to at least one other health care provider.

Chronic illnesses such as cancer, diabetes and arthritis disproportionately burden seniors.

Thus, the scoping review at the intersection of senior citizens, EHRs and privacy, will focus on these prominent chronic illnesses in order to identify relevant literature.

Cancer is one of the leading causes of death within Canada. According to the Canadian Cancer Society (2012), an estimated 186,400 new cases of cancer (excluding 81,300 non-melanoma skin cancers) and 75,700 deaths from cancer will occur in Canada in 2012. Notably, the Canadian Cancer Registry Database showed 86,406 new cancer diagnoses in senior patients in 2006, a 9% increase since 2000. Age is a key factor in cancer burden, with 69% of new cases and 62% of cancer deaths occurring among those 50 to 79 years of age.

Likewise, diabetes is a prevalent chronic condition among Canadian senior citizens. The Canadian Community Health Survey showed an increase in the diagnoses of diabetes (13.5% to 18.1%) in seniors between 2003 and 2009 (Canadian Institute for Health Information, 2011). According to Statistics Canada (2010), common complications of diabetes include heart disease and stroke, vision problems or blindness, kidney failure, and nerve damage. Moreover, arthritis is a highly prevalent chronic condition that increases with age and has implications for Canada's ageing population. In 2008, Statistics Canada revealed that 15.3% of Canadians aged 12 or older reported a diagnosis of arthritis (4.3 million): 12.0% of males (1.7 million) and 18.5% of females (2.6 million). Moreover, arthritis is highly associated with mobility limitations and dependency in activities of daily living. According to the Canadian Institute for Health

Information (2011), although the prevalence of arthritis slightly declined since 2003, it still constitutes a large proportion of chronic illness diagnoses in seniors (41.8% in 2009).

As Canadian senior citizens are disproportionately afflicted with chronic conditions, they tend to utilize a wider range of health care services. Even 25 years ago, the elderly already occupied one-third of all hospital beds and utilized one-quarter of total health care services (Mirolla, 2004). As their proportion within the population increases, their consumption of clinical services will drastically escalate. According to the Canadian Academy of Health Sciences (2010), senior citizens experience large variability in their care needs. More specifically, the elderly are likely to experience a need for acute care, either within the emergency room or prolonged hospitalization, as well as community or long-term care. As senior citizens are frequently moving in and out of various segments of the health care system, their privacy must be sufficiently protected, particularly within the impending nation-wide EHR system.

Electronic Health Records

Within the next several years, a comprehensive electronic health record system will be established throughout the nation. Although a pan-Canadian EHR system can offer a multitude of clinical and administrative benefits, privacy concerns must be considered prior to implementation.

Promises.

Electronic health records (EHRs) are owned by health care providers and are anticipated to offer a long-term repository of patient information generated by one or more clinical encounters in a variety of care settings (Hill & Powell, 2009). According to

Baron (2011), electronic health records have the potential to improve the safety, quality and efficiency of patient care. With respect to safety, EHRs can reduce prescribing errors by flagging erroneously entered drug orders, noting drug allergies and highlighting potentially life-threatening drug interactions. This is of particular concern for seniors who often take multiple medicines. In regards to quality, electronic health records can contain a reminder function for preventative care, such as vaccinations or cancer screening. As well, EHRs can manage chronic conditions over time, by tracking laboratory test results and sharing that information across a patient's care team. Furthermore, electronic health records can act to promote public health by enabling the collection of data derived from a multitude of patients, which can assist public health officials in decision making.

Challenges.

Proponents of electronic health records argue that the paper-based records which predominate the Canadian health care system lack coherence and organization. According to Rothstein and Talbott (2006), typical paper-based health records are a collection of disparate notes, laboratory tests and clinical encounters, which involve a range of conditions and ailments over a prolonged period of time. Paper records potentially merge routine clinical data with highly sensitive health information, such as mental health status, genetic test results and sexually transmitted diseases. On the contrary, EHRs can permeate through every element of clinical work flow and facilitate communication amongst distinct health care providers (Terry & Francis, 2006). Indeed, electronic health records offer vast organizational benefits, as they allow users to efficiently locate and access patient health information. However, it is a challenge for EHR developers to bring

coherence within diverse types of health records and users while securing the privacy of patient health information.

Information Privacy

Information privacy is very significant for health care consumers as it is associated with notions of access, control and disclosure. As a result, privacy is highly relevant in light of imminent EHR developments.

Privacy and seniors.

Privacy is significant for all patients, as it is closely linked to notions of autonomy and integrity. The Supreme Court of Canada has deemed privacy as pivotal to liberty in a modern state and defined personal health information as “information that goes to the personal integrity and autonomy of the patient” (D'Agostino & Woodward, 2010). Thus, according to Angst (2009), personal health information forms the “intellectual capital” through which humans craft their lives and establish dignity and autonomy. Electronic health records elicit privacy concerns for elderly individuals suffering from chronic illnesses, as they have the capability of sharing vast quantities of personal health information across numerous health care settings within several minutes. The Auditor General of Ontario (2009) estimates that there are about 2,000 health care transactions in Canada every minute, or more than 1 billion transactions every year. On a yearly basis, such transactions are comprised of 440 million laboratory tests, 382 million drug prescriptions, 332 million visits to physicians' offices, 35 million diagnostic images, as well as 2.8 million patient hospitalizations.

As privacy is implicated across nearly all patient care processes and is linked to

one's autonomy and integrity, privacy breaches must be framed and interpreted as profound violations. According to Balka, Rodje and Bush (2007), privacy considerations cannot be disregarded or solely viewed from a technological perspective and labelled as minor technical problems. Indeed, such a limited view of privacy deems it as insignificant and inconsequential. Instead, the larger implications of privacy must be considered and privacy must be conceived as a “way of knowing” and a “way of doing,” particularly in regards to vulnerable populations.

Personal health information protection act (PHIPA).

The Personal Health Information Protection Act (PHIPA) is a legislation within Ontario which puts forth requirements for the preservation of patient privacy. PHIPA received royal assent on May 20th, 2004, and the majority of its provisions came into force on November 1st, 2004. The act contains ten key principles. There are provisions on consent, accountability, openness, security, accuracy, as well as restrictions on the collection, use and disclosure of personal health information. Furthermore, PHIPA contains provisions regarding the enforcement and administration of the act. The act predominantly applies to health information custodians and recipients. The health information custodians listed in PHIPA include health care providers, public hospitals, long-term care facilities and the Ministry of Health and Long Term Care. Under the obligation to PHIPA, health information custodians (HICs) are responsible for protecting the privacy of personal health information within their custody, which also includes information that they permit their agents to collect and disclose. The information recipients are individuals to whom HICs disclose patient information. Recipients often

are physicians, nurses, pharmacists and clinical managers. PHIPA prohibits recipients from utilizing or disclosing patient health information for purposes other than what the health information custodian was authorized for its use. For instance, express consent is required prior to a recipient's disclosure of patient health information for marketing, research or fund raising purposes.

PHIPA conceptualizes personal health information (PHI) in broad terms. According to the act, personal health information is considered to be identifying information about an individual in either oral or recorded form, 2004, section 1(4). Personal health information relates to an individual's physical or mental health, including one's health history, 2004, section 1(4). Furthermore, personal health information concerns the provision of health care to the individual, including the identification of the provider, 2004, section 1(4). Moreover, PHI relates to an individual's plan of service, payments, eligibility or coverage for health care, 2004, section 1(4). According to the act, PHI also pertains to the donation of a body part or bodily substances of the individual, or PHI is obtained from the testing or examination of any body part or bodily substance, 2004, section 1(4). Lastly, PHI concerns an individual's health card number or the identity of their substitute decision maker, 2004, section 1(4).

This paper will largely examine the information practices employed by HICs, in relation to chronically ill and elderly individuals. The act defines information practices as “when, how and the purposes for which the custodian routinely collects, uses, modifies, discloses, retains or disposes personal health information”, 2004, section 1(2). Furthermore, PHIPA conceives information practices as the “administrative, technical and

physical safeguards and practices that the custodian maintains with respect to the information”, 2004, section 1(2). Although PHIPA conveys rigorous requirements for the protection of patient privacy, there are certain gaps within the act which may not be aligned with the impending nation-wide EHR system. These shortcomings will be closely analyzed in relation to the fundamental privacy requirements of elderly individuals living with chronic conditions, who are a highly vulnerable patient cohort.

Aims of Major Research Paper

A scoping review of literature with a focus on Canada was undertaken in order: 1) to examine the areas where privacy breaches of personal health information are likely to occur within the use of EHRs for chronically ill and elderly citizens, 2) to examine the impact of such breaches on the chronically ill and elderly, and 3) to examine the representation of the interests of chronically ill and elderly patients, in relation to multiple interest groups (i.e., government and manufacturers) within EHR development and implementation.

Methods

A scoping review is the primary research method utilized within this project as a means of locating pertinent literature. According to Arskey and O'Malley (2005), a scoping review can map the key concepts underlying a research area and the main sources and evidence available. A scoping review can be undertaken as a stand-alone project, particularly when an area is complex or has not been comprehensively reviewed before. According to the authors, there are four main reasons why scoping studies are undertaken. Firstly, a scoping review helps to examine the extent, range and nature of a

field of knowledge. Secondly, a scoping review aids in determining whether it is feasible to undertake a full systematic review. Thirdly, a scoping review helps to summarize and disseminate findings. Lastly, a scoping method can locate gaps within the literature. For the major research paper, the scoping review summarized pertinent findings and located the gaps, in order to identify future directions at the intersection of EHRs, the privacy act of Ontario, and the personal health information of chronically ill and elderly individuals.

Differences between a Scoping Review and Other Literature Reviews

A scoping review was utilized within the research project. A scoping review was employed instead of a Cochrane review or narrative summary, as a means of effectively synthesizing and analyzing the located literature.

Cochrane review.

A scoping review greatly differs from a traditional Cochrane systematic review. The key dimensions of these differences are: the types of questions examined, the application of inclusion and exclusion criteria, the information sources included and the use of quality criteria. According to the Cochrane Collaboration (2012), a Cochrane review is conducted for a narrowly defined research question (e.g., Can antibiotics help relieve the symptoms of a sore throat?). Thus, Cochrane reviews develop inclusion and exclusion criteria in a stringent and linear manner. However, the questions examined in a scoping review are broad and thus, the inclusion and exclusion criteria are developed in an iterative manner by conducting a preliminary search. Indeed, for a scoping review, Arskey and O'Malley (2005) do not recommended strict limitations in the use of terms to identify relevant studies. Therefore, a scoping review is an iterative rather than a linear

process, and researchers are required to actively engage with each research stage in a reflexive way. As a result, scoping reviews include sources of information which go beyond primary research, while Cochrane reviews solely include primary research. Another important difference is the application of quality criterion to the selected studies. The Cochrane review applies design-specific criteria and values experimental (e.g., randomized controlled trials) over non-experimental studies (e.g., cohort studies). At the same time, it excludes qualitative studies or discussion papers. On the other hand, the scoping review does not assess the quality of included studies because the emphasis is given to the relevance of the selected literature.

On the whole, a scoping review produces a broad map of located evidence, which is sufficiently transparent and can be used by and for applications beyond the author's originally intended purpose (Armstrong, Hall, Doyle & Waters, 2011). On the other hand, Cochrane reviews are conducted with primary research in health care and health policy and typically investigate the effects of interventions for prevention, treatment and rehabilitation.

Narrative summary.

A narrative summary greatly differs from a scoping review. According to Dixon-Woods et al. (2005), a narrative summary typically involves the selection, chronicling and ordering of evidence to produce an account of the evidence. More specifically, a narrative summary can be used to emphasize the sequential character of phenomena, or it can integrate juxtaposing evidence side by side. However, a narrative summary is largely an informal approach and is often subject to criticism due to its lack of transparency. On the

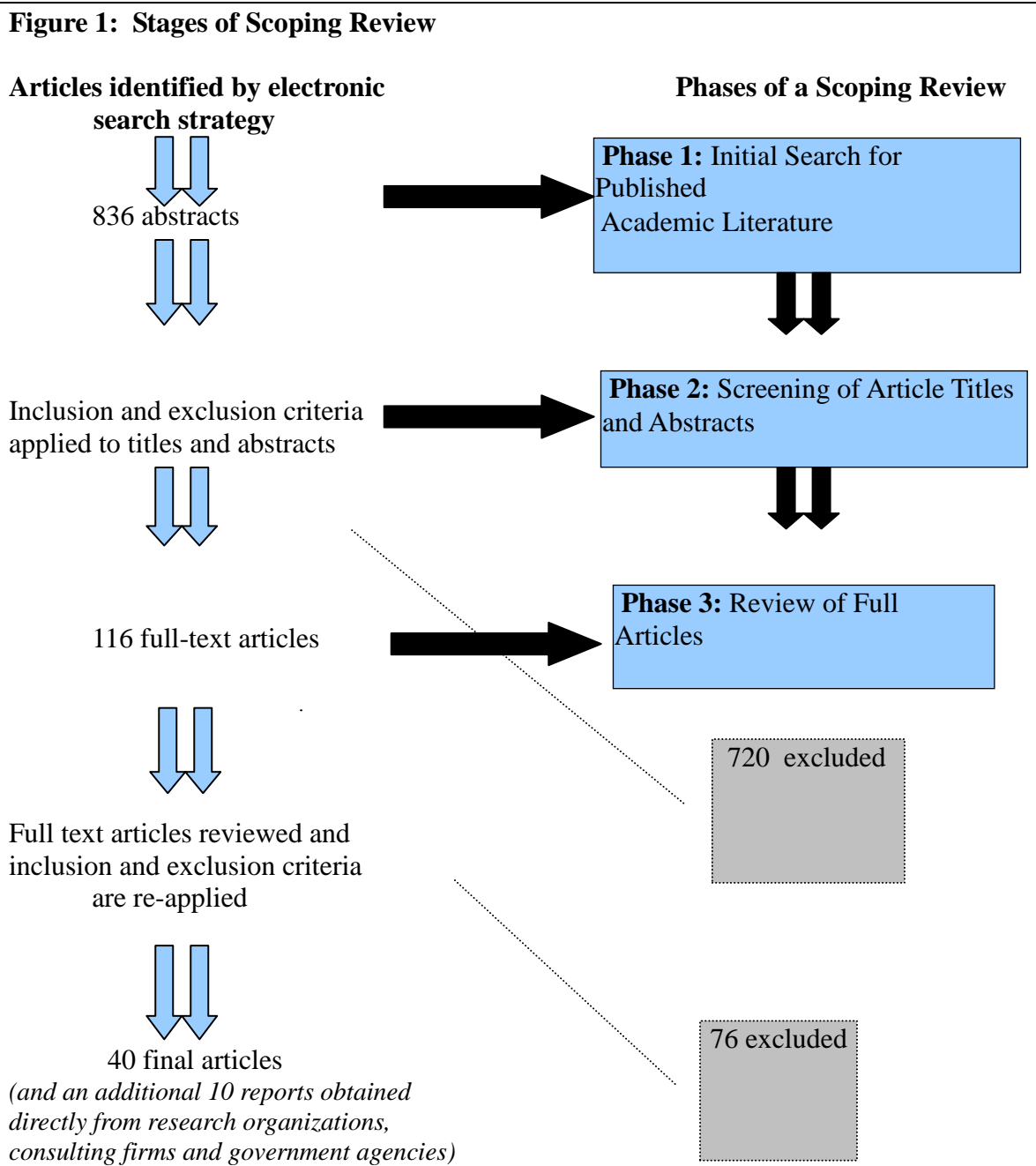
other hand, as stated by Levac et al. (2010), a scoping review is constituted by a clearly articulated scope of research. Unlike a narrative summary, a scoping review can effectively highlight the gaps existing in the literature. As well, although a narrative summary can record and order located data, a scoping review provides opportunities for consumer and stakeholder involvement. According to Anderson et al. (2008), the optional final phase of a scoping review consists of a stakeholder consultation, whereby those who commissioned the research can be informed of the results. More recently, expert interviews are also recommended for scoping review to identify in-progress work or unpublished reports (Levac et al., 2010).

Rationale for Selecting a Scoping Review

A scoping review was chosen for the research project at hand, as this particular method provides a mechanism through which to summarize and report relevant research findings and identify gaps for future directions. The scoping method is appropriate for this project as the research topic is very narrow, but the relevant literature is likely located in multiple sources. The scoping review acts like a funnel, as it locates the relevant literature and omits digressive material. As well, a scoping method elicits guidelines through which located evidence can be organized, which assists in reviewing, comparing and contrasting the obtained data. Furthermore, a scoping method can locate pertinent gaps within the literature concerning whether EHRs can adequately preserve the privacy of chronically ill seniors, in relation to provincial legislation.

Stages of a Scoping Review

The conducted scoping review employed a specific search strategy which consisted of four stages (Figure 1). However, the stages were iterative rather than linear, as the student researcher often returned to a prior stage in order to build upon it. The primary stage constituted the search strategy and initial search for published academic literature. Inclusion and exclusion criteria were established within this stage. The article titles and abstracts were screened within the second stage of the scoping review. Stage three consisted of a full review of located articles. The final stage of the scoping review consisted of data extraction and the synthesis of included articles. Overall, the scoping review yielded a total of 836 abstracts, 116 sources were deemed as relevant, but only 40 articles reached the final selection. More details on the types of reviewed literature are provided in Appendix 2. In addition to the included articles, an additional 10 reports and publications were directly located within prominent research organizations, consulting firms and government agencies.



Stage 1: search strategy and initial search for published academic literature.

Three search strategies were utilized within the project- database searches, journal hand-searching and web-site searching of key health organizations, consulting firms and government agencies. The search was limited to articles published in English, during

2004, January to 2012, May. Search terms included: electronic health records or EHRs, chronic illness or chronically ill or chronic disease or diabetes, arthritis or cancer, privacy or Personal Health Information Protection Act or PHIPA, as well as elderly or senior citizen. However, due to the variability between certain databases, some search terms were slightly altered (e.g., “senior citizen” or “elderly adult”). Search terms were entered into social sciences, medical, technical, scientific and psychology databases using Boolean operators. The databases that were searched are: Scholars Portal, Jstor, CBCA Complete, PubMed, Medline (Ovid), Proquest, PsycInfo, Scopus, Ebsco, Canadian Health Research Collection, REHABDATA, CINAHL: Cumulative Index to Nursing and Allied Health, Social Work Abstracts, Nursing and Allied Health Source, Canadian Periodicals Index Quarterly, Sociological Abstracts and Social Science Research Network (SSRN) (Appendix 1). Evidence was collected from both quantitative and qualitative scholarly literature, as well as discussion papers, information guides, recommendation reports, literature reviews and commentaries.

In order to obtain pertinent legal information regarding the privacy implications of electronic health records and PHIPA, three journals were examined as well. The legal journals that were searched were: Intellectual Property Law Journal, Health Law Journal and the Canadian Journal of Law and Technology. The literature search was conducted through the York University library website and a student log-in provided access to these resources. Moreover, in order to obtain pertinent information regarding the current state of affairs within EHR development, chronic disease and provincial and federal policy, an additional 10 reports and publications were directly located within prominent research

organizations, consulting firms and government agencies. Such agencies and organizations consist of: The Chronic Disease Prevention Alliance of Canada (CDPAC), The Canadian Academy of Health Sciences (CAHS), Canadian Institute for Health Information (CIHI), Office of the Auditor General of Ontario, Information and Privacy Commissioner of Ontario, Canada Health Infoway, Canadian Cancer Society, eHealth Ontario, University of Western Ontario: Ivey Centre for Health Innovation and Leadership and the electronic law database of the Government of Ontario.

Stage 2: Screening of article titles and abstracts

The electronic database search yielded a total of 836 articles, excluding duplicates. A single reviewer (student researcher: CZ) screened the titles and abstracts against the established inclusion and exclusion criteria (Table 1), which resulted in the identification of 116 relevant articles for which full-text copies were retrieved. Ten reports or publications were also identified through searching web-sites of prominent research organizations, consulting firms and government agencies.

Table 1. Inclusion and Exclusion Criteria

Inclusion	Exclusion
Includes but is not limited to: <ul style="list-style-type: none"> ● Literature applicable to chronic diseases such as cancer, diabetes and arthritis ● Literature that can be applied to senior citizens (65 years of age and over) 	Excludes: <ul style="list-style-type: none"> ● Literature that is published prior to 2004, as PHIPA came into effect on November 1st, 2004 ● Literature that is published in a language other than English ● Literature that concerns nations outside of North America, unless used as a direct comparison to Canada

Stage 3: Review of full articles

The 116 retrieved articles and 10 reports were reviewed. The journal article or document was typically printed and relevant information was highlighted and marked. The source was designated by a number (i.e. Source 23) for easy reference and retrieval. The inclusion and exclusion criteria were reapplied to 116 articles by the student researcher and 40 were selected. The activities for Stage 2 and 3 were iterative in nature. For example, the inclusion and exclusion criteria could not be clearly applied to some of the retrieved titles and abstracts during Stage 1. As a result, for these abstracts, full-text articles were retrieved and the criteria were reapplied.

Stage 4: Data extraction and synthesis of included articles

Within the final stage of the scoping review, a thematic analysis was conducted. The final stage of a scoping review was iterative in nature. For instance, if the title and abstract and subsequent material within the publication were relevant to the topic, then notes were taken on significant findings and themes.

Within phase four of a scoping review, significant information from the literature was charted in an Excel spreadsheet. The chart headings included: author(s), year of publication, study location, intervention type, duration of intervention, study population, aims of study, methodology, outcome measures and important results. The use of these categories allowed the data to be sifted and sorted according to key themes and issues. A relevant example is represented Appendix 2 and Appendix 3.

As the scoping review process is iterative, the chart was continually updated by the student researcher by locating more information, establishing links and drawing

conclusions. Within the chart, the most significant aspects of each study were drawn out. As a result, the Excel chart was utilized as a reference guide and a method through which the data was comprehensively observed and re-organized. Overall, the final stage of a scoping review consisted of analyzing the obtained data. Furthermore, the chart and compiled notes highlighted the distinct themes and potential gaps within the literature. The researcher applied a theoretical lens (discussed below) in order to interpret the findings and put forth recommendations following the analysis.

The final stage of the scoping review was based on the recommendations put forth by several authors. Firstly, Levac et al. (2010) emphasized that the final stage of a scoping review allows the researcher to consider the meaning of the findings in relation to the overall research question. As a result, a descriptive and analytical method must be employed, which involves describing information in a way that is meaningful to the project. Furthermore, according to Howitt & Cramer (2007), within a thematic analysis, a researcher must identify a limited number of themes which adequately reflect their textual data. After locating and becoming familiar with the data, a researcher must apply brief verbal descriptions to small chunks of data.

Theoretical Lenses Information Interpretation of Findings

Despite the advantages of a scoping review method as described by Arskey and O'Malley (2005), the method lacks the explicit incorporation of a theoretical lens. The lack of a distinct lens is problematic, as it does not provide a clear perspective through which to approach the data. The selection of a lens within a scoping review is indispensable, particularly if a researcher intends to put forth recommendations. Thus, concepts were

drawn from both the ecological systems theory and political-economic lens, as a means of analyzing the themes which have emerged from the literature.

Ecological systems theory.

Bronfenbrenner's Ecological Systems Theory provides a way to establish a connection between the self and the broader social, political and economic environment. The ecological systems theory was applied to this project, as a means of linking the needs of chronically ill and elderly individuals to the structure and function of the impending pan-Canadian EHR system, as well as to the encompassing political-economic environment.

Bronfenbrenner's ecological systems theory (1979) is a pivotal landmark in developmental science and psychology. According to Darling (2007), the ecological systems theory emphasizes the interrelationship of the various processes which guide life-span development, and their contextual variation. Ecological systems theory represents human development through a manner where everything is seen as interrelated, and our knowledge of development is influenced by context, culture and history. More specifically, Bronfenbrenner's ecological systems theory looks at numerous layers such as an individual's biology, immediate family, community and societal landscape, in relation to one's development (Paquette & Ryan, 2001). Indeed, Bronfenbrenner examines how changes within the layers are bi-directional, as change or conflict in one layer will impact another.

As described by Paquette and Ryan (2001), the layers formulated by Bronfenbrenner consist of: the microsystem, mesosystem, exosystem, macrosystem and chronosystem. The microsystem is the layer closest to an individual and it consists of

structures with which he/she has direct contact, such as their family. The mesosystem constitutes the connection between the structures of an individual's microsystem (e.g., the connection between a patient and their healthcare providers). Furthermore, the exosystem is the larger social system which does not impact an individual directly, but the individual feels its impact when he/she interacts with their microsystem (e.g., physical layout of their home). Moreover, the macrosystem is the outermost layer and is comprised of cultural values, customs and laws. Thus, the macrosystem has a significant cascading influence upon the other layers. Lastly, the chronosystem is related to timing, in relation to an individual's environment. Indeed, as one ages, they react differently to particular occurrences and life events.

The ecological systems theory was applied to this project in order to facilitate a link between individual and multi-level factors. Bronfenbrenner's ecological systems theory acts like an "adhesive" within this paper, as it unifies specific and comprehensive concepts across levels. However, the ecological systems theory does not explicitly question the power difference across these systems. Thus, the political-economic lens has been included as a means to examine potential issues due to the vulnerability of chronically ill and elderly individuals, which is the focus of this major research paper.

Political-economic lens.

According to Rausser, Swinnen and Zusman (2011), in any public policy making process, political and economic forces are involved in resolving the strategic interactions among the divergent interests. The foundation of the political-economic lens emerged from the early work of Nash (1951) and Harsanyi (1967). These authors emphasized the

concept of “bargaining power”. Current conceptions and applications of the political-economic lens focus on the “distribution of power” between the government and various interest groups. More specifically, a political-economic lens examines how powerfully linked economic and political forces structure social life, while also exploring the forms of resistance to such forces (Armstrong, Armstrong, & Coburn, 2001).

According to Rausser et al. (2011), all collective action organizations and the government consist of a “center” which directs group actions and peripheral participants. The choices and decisions of the powerful “center” impact the actions and well-being of peripheral, less influential participants. The “center” also consists of individuals with their own private interests. Once the policies are designed and implemented, it is assessed which groups become “winners or losers”, as some groups will bear the burden of the established policy, while others may greatly benefit. Consequently, the political-economic lens attempts to explain how peripheral participants are influenced by the “center’s” choices.

As argued by Armstrong et al. (2001), the political-economic lens also includes the ideas, discourses and practices that dominate or subvert existing relations of ruling. This brings one’s attention to the social determinants of health. Thus, through examining relations of inequality and ruling, one can explore the central question of “who benefits?” In my view, the political-economic lens is necessary to examine the vulnerable status and distinct needs of seniors suffering from chronic illnesses.

Findings

A thematic synthesis of the literature selected through a scoping review has identified six areas where privacy breaches within electronic health records typically occur. These infractions can drastically impact the privacy of elderly individuals suffering from chronic illnesses. Firstly, the lack of interoperability between electronic health record platforms and the absence of integrated policies and procedures amongst jurisdictions will be discussed. Furthermore, potentially problematic secondary uses of personal health information and the creation of databases derived from EHRs will be examined. The issue of accountability due to multiple health information custodians will be described, as well as haphazard EHR system malfunctions. In addition to the five areas where privacy breaches often occur, the incompatible interests of divergent stakeholders will also be examined.

The themes which emerged from the located literature were analyzed through Bronfenbrenner's ecological systems theory. More specifically, it was discerned whether the emergent themes focus on individual-level or broad macrosystem factors such as cultural values, customs and laws. According to Darling (2007), even though the macrosystem has a significant cascading influence upon other lower-level layers, the central force is the “active person”. Rather than simply reacting to external factors, the individual often locates their own environment and evokes responses from it. As a result, the ecological systems theory has highlighted whether existent academic literature targets or meets the needs of elderly individuals who are living with chronic conditions. Furthermore, the power differences across the micro, meso and macro layers of the

ecological system were examined and interpreted by applying the political-economic lens, informed by the work of Rausser et al., in particular.

The first section presents descriptive information about the 50 selected articles and reports. Subsequently, the six identified themes are presented along with critical interpretation by the student researcher.

Types of Literature Available

The 50 selected articles and reports included 27 discussion papers, nine research studies, two information guides, seven information guides with recommendations, two commentaries and three literature reviews (Appendix 2). Of the nine research studies, two were case studies, three were surveys, one was a pretest-posttest design, one was a longitudinal retrospective study, one was a focus group and one was a randomized control trial. The majority of the articles and reports were from the United States (n=25) and Canada (n=22), and only a few originated from Western Europe (n=3). Moreover, the majority of the reviewed articles and reports were fairly recent, as they were published from 2008 onwards (n=34). Out of these, only 11 references discussed chronic illnesses, while nine discussed both senior citizens and chronic illnesses. A complete list of these 50 reviewed studies and report is included in Appendix 3.

Literature Themes

Theme 1: lack of interoperability between electronic health record systems.

There is a lack of interoperability between electronic health record platforms. The major issues are: the delayed development of EHR interoperability, barriers that restrict interoperability and the negative consequences for vulnerable patient groups.

Semantic interoperability between electronic health records is required for their functionality. According to Hoffman and Podgurski (2008), semantic interoperability is the ability of information systems to exchange data on the basis of shared, predetermined and negotiated meanings of various terms. Semantic interoperability implies that the entire contents of an EHR which are produced or altered within one system, can be transmitted to other systems as well. The transmission must allow the receiving system to interpret and apply the incoming personal health information. System interoperability allows health care providers to access relevant information about their patients, including medical histories, allergies and drug lists, regardless of where the patient has been previously treated.

In 2009, the Office of the Auditor General of Ontario highlighted six key components that must be shared within a pan-Canadian electronic health record system. These components are: client registry, provider registry, diagnostic imaging, drug information, laboratory data, clinical reports and immunizations. These essential EHR components must be linked to a portal viewer known as the Health Information Access Layer (HIAL). However, the Office of the Auditor General noted that development of an interoperable HIAL is at the infancy stage within Ontario. More specifically, a provincial HIAL integration project with an allotted budget of \$237 million, has not been initiated as of yet. An accompanying consent-management module which allows patients to view and restrict how their personal health information is utilized has not been developed either. Due to the absence of such a system, all of the applications have been operating in isolation. Such separation is problematic, as each system component employs distinct

privacy and consent controls. Furthermore, there is a perception that by keeping the systems separate, the chances of privacy threats to patient information would be reduced. However, this may not be the case, as providers will be forced to fax or mail paper-based health information which holds higher threats to patient privacy. Although the reviewed literature did not specify the vulnerability of chronically ill and elderly patients, the lack of interoperability increases privacy risks for this group, as they typically have an extensive medical history comprised of numerous care interactions.

The largest barrier to the lack of interoperability between electronic health records is disparate medical terminology (Hoffman & Podgurski, 2008; Daghli & Archer, 2009). According to Hoffman (2010), the lack of a standardized language between EHR components impacts the layout and accessibility of the record, which may have implications for patient privacy. Due to fragmentation between electronic health records, information about a distinct medical concern may be found on multiple screens and could be organized by varying factors, such as date of service. Furthermore, awkward electronic health record displays may make it difficult for users to locate pertinent patient information. Thus, providers may need to go through additional portions of a patient's health record in order to obtain what they sought, which can elicit privacy breaches. Furthermore, as health care providers may find it difficult to follow a patient's medical history and progression, they may print portions of the patient's record, which can elicit additional privacy concerns.

The lack of a singular EHR standard can elicit negative consequences for chronically ill and elderly individuals as their personal health information is frequently

accessed and altered. From the perspective of the ecological systems theory, it appears that the lack of a common EHR standard is due to discordance at the macrosystem level, as it involves the differing goals of the federal and provincial government and independent not-for-profit organizations such as Canada Health Infoway. The political-economic lens, as informed by Rausser et al. (2011), emphasizes that the policy-making process is largely determined by government bureaucracy and influential stakeholders. Consequently, within policy-making, these groups compete by spending money, time and effort, in order to influence policy implementation. However, the located literature does not discuss the impact of such macrosystem processes on the individual, particularly on vulnerable populations such as the chronically ill and elderly. Possibly, the lack of representation of chronically ill seniors is a reflection of inadequate resource investment, including time and funds, by the provincial and federal bodies.

Theme 2: lack of integrated policies and procedures amongst jurisdictions.

There is a lack of integrated policies and procedures amongst jurisdictions for the development and implementation of EHR systems. In this respect, the major issues are the differences in: jurisdictional goals, health information acts, nature of patient consent, as well as accountability and role ambiguity of key players.

Although a pan-Canadian electronic health record system is intended to be comprehensive and standardized, a large amount of variability exists amongst Canadian provinces and territories. Such disparities can potentially threaten patient privacy, particularly in the event of a re-location. According to D'Agostino and Woodward (2010), the lack of a singular overarching electronic health record objective is largely due to the

unique goals of various jurisdictional EHR initiatives. Each system is meant to serve patient populations of varying sizes and demographics, to support a variety of health care needs and is comprised of distinct types of personal health information. Although the individualized needs of the utilizing parties are taken into account during the development phase of EHRs, issues of connectivity and comprehensibility may not be considered, which may impact patient privacy. Thus, there is a need to overcome jurisdictional variability by concrete, nation-wide goals and guidelines.

In order to achieve this, several Canadian provinces have enacted health information policies or acts. However, according to the Canadian Standing Committee on Social Affairs, Science and Technology, there is variation in nation-wide privacy laws and personal health information access policies: “Differences in rules on how the scope of purpose is defined, the form of consent required, the conditions for substitute decision-making, the criteria for non-consensual access to personal health information, periods for retention of data, and requirements for destruction, to name but a few, must be seriously addressed in order to enable the development of EHR systems” (D'Agostino & Woodward, 2010).

The lack of compatibility between jurisdictional policies is evident when comparing provincial patient consent processes. For instance, Ontario's Personal Health Information Protection Act has established an implied consent model for the collection, use and disclosure of personal health information, 2004, section 18(2). As a result, consent is considered to be implied if health information is disclosed to health information custodians for the purpose of providing care, 2004, section 18(3). Similarly,

the Saskatchewan Health Information Protection Act (HIPA) also abides by a similar implied consent model, whereby consent is considered as implied when personal health information is necessary for providing health services, 2004, section 6(1). Conversely, in Manitoba, electronic disclosure of personal health information is permitted without consent (D'Agostino & Woodward, 2010). However, what will occur if a patient who has withdrawn their consent within Ontario, relocates to Manitoba? How can their consent preferences be recorded and honored? According to Darling (2007), Bronfenbrenner's ecological systems theory emphasizes the interrelationship between the individual, contextual variability and individual difference. Indeed, in order to understand the development of individuals, objective and detailed measurements of the social context must be employed. However, the located literature does not consider how broad jurisdictional differences may elicit privacy breaches for chronically ill and elderly residents, particularly if they relocate from one health care setting to another.

Some progression has facilitated the inter-jurisdictional transfer of personal health information. For instance, Canada Health Infoway (2010) explicitly states that “Once information is disclosed to a custodian or trustee in a second jurisdiction (and thereby has been indirectly collected by a custodian or trustee in the second jurisdiction), it becomes subject to the information handling legislation and policies of the second jurisdiction”. However, an individual's consent choice may not be upheld by the receiving jurisdiction, which can elicit threats to patient privacy.

Despite the elicitation of suggestions, no clear solutions have been enacted for the inter-jurisdictional transfer of health information. According to D'Agostino and

Woodward (2010), such suggestions include a notice system which will alert the receiving province or territory of the original consent information, so that consent options can be coordinated. Furthermore, the establishment of a nation-wide set of electronic health record best practice guidelines or a singular implementation strategy has also been proposed. The inter-jurisdictional misalignment must be resolved prior to the implementation of a nation-wide EHR system, as patient privacy will be threatened.

In addition to inter-jurisdictional policy misalignment, there is also role ambiguity amongst provincial and federal organizations which are involved in EHR development. Canada Health Infoway (2011) is an independent not-for-profit corporation which acts as a “strategic investor” in order to foster the development of electronic health records within Canada. Canada Health Infoway is responsible for developing blueprint standards for EHRs, which all provinces and territories must adhere to. However, the organization is not responsible for enforcing their regulations and applying penalties. Indeed, Canada Health Infoway has not been following up with provinces and territories regarding conformity with the blueprint and no concrete plan has been developed to manage the variance between EHR projects (D'Agostino & Woodward, 2010).

In addition to a lack of enforcement, Canada Health Infoway is not accountable for evaluating whether electronic health record systems can adequately protect patient privacy. According to D'Agostino and Woodward (2010), although Canada Health Infoway ensures that EHR projects meet the security and privacy requirements put forth by the blueprint, it has no responsibility to discern whether the system complies with jurisdictional privacy laws. Furthermore, the organization does not address issues of

ownership in relation to the personal health information contained within EHRs. As well, the organization does not address how privacy breaches can drastically impact vulnerable patient groups, such as the elderly and chronically ill. According to Darling (2007), “meaning” within the ecological systems theory is created by the individual as a product of all their experiences. However, as Canada Health Infoway does not examine issues of information ownership, the meaning that patients attach to their privacy is not considered.

Following the establishment of nation-wide standards by Canada Health Infoway, eHealth Ontario is responsible for meeting those requirements at the provincial level. Ehealth Ontario is a special branch of the Ministry of Health and Long-Term care in Ontario. The organization's primary role is to harness information technology and innovation in order to support the federal EHR strategy (eHealth Ontario, 2011). Its primary goal is to have an interoperable electronic health record system established across the province by 2015. However, Ontario eHealth is taking a piecemeal approach to developing an EHR system. According to D'Agostino and Woodward (2010), eHealth Ontario is focusing on a sub-system of EHRs by emphasizing diabetes management. This approach seems counter-intuitive as it may be more appropriate to develop a standardized EHR system appropriate for all Ontario residents and subsequently tailor that system to meet the unique needs of individuals suffering from chronic illnesses. According to Rausser et al. (2011), the political-economic lens emphasizes that the implementation strategies of public sector agents can lead to both intended and unintended consequences. In this case, it seems that a focus on diabetes management can lead to unintended consequences of information asymmetry, participation restriction and goal

incompatibility. These might elicit a negative impact on the overall health of the population.

It is necessary for eHealth Ontario to develop an approach which will maintain the privacy of vulnerable patient groups such as elderly individuals living with chronic disease. As conceptualized by Paquette and Ryan (2001), the ecological systems theory demonstrates that economic and political policies which support individuals during a time of technological change are urgently required. Thus, the development plan must ensure that the EHRs are able to sufficiently protect the privacy of healthy Ontarians, prior to meeting the distinct needs of those suffering from chronic illnesses.

Theme 3: secondary uses of personal health information.

There are several inconsistencies centered around secondary uses of personal health information within electronic health records. Such inconsistencies are: a lack of comprehensive guidelines at the policy level, the ambiguity of deidentification processes and a lack of assessment of the impact that secondary uses of health information would have on vulnerable patient groups.

Electronic health records can offer numerous benefits for health research.

Electronic health records can allow for the creation of databases which consist of patient records from one or more health networks (Hoffman, 2010; Willison, 2009). These databases can allow researchers to conduct comprehensive observational studies based on the clinical experience and demographics of millions of patients with diverse backgrounds. Studies that would take years to complete, may be accomplished in months. There are generally two main purposes for why researchers seek access to information

contained in a health record. The primary reason is to extract data from the record and link it with information from other records, without an interest in the individual's identity and without an intention to establish contact with the individual. Conversely, information contained in a EHR can aide in contacting patients in order to invite them to participate in a study which requires direct data collection from the individual.

The Personal Health Information Protection Act puts forth several provisions regarding the utilization of personal health information for research purposes. According to PHIPA, “research” means a “systematic investigation designed to develop or establish principles, facts or generalizable knowledge, or any combination of them, and includes the development, testing and evaluation of research”, 2004, section 1(2). Furthermore, PHIPA indicates that “...a health information custodian may use personal health information about an individual only if the custodian prepares a research plan and has a research ethics board approve it...”, 2004, section 37(3). In regards to utilization of personal health information for marketing or commercial purposes, PHIPA posits that “a health information custodian may collect, use or disclose personal health information about an individual for the purpose of fund raising activities only where, (a) the individual expressly consents; or (b) the individual consents by way of an implied consent and the information consists only of the individual’s name and the prescribed types of contact information, 2004, section 32(1). Although PHIPA puts forth several guidelines for the utilization of patient information within research, there are no clear standards on how personal health information must be safeguarded, particularly for vulnerable patient groups.

The deidentification of personal health information is deemed to be a viable method of protecting patient identity within health research. According to Rothstein (2010), deidentified information is information that has been removed of data elements associated with an individual. Deidentified information is one of several levels of identifiability between “anonymous information,” which cannot be associated with an individual and information containing “direct identifiers,” such as an individual's name. Deidentified information is situated in a gray area between information that is identifiable and requires legal oversight and non-identifiable information, which does not merit any legal protection.

Even though the process of deidentification seems like a full-proof method to protect patient privacy within secondary uses of personal health information, there are several drawbacks to deidentification practices. Firstly, the process is variable and dependent on the type of electronic health record system in use. According to Rothstein (2010), EHR systems do not typically allow for single click deidentification. An EHR system's ability to deidentify information is dependent on the system's means to analyze free text clinician notes, as well as its' ability to deidentify scanned laboratory, imaging and others reports. Consequently, traditional “white out” strategies that are typically used for paper-based records may need to be employed for certain EHR systems. However, such conventional methods of erasure may compromise patient privacy, as patient records will be printed and manually handled. A second complexity inherent within deidentification is concerned with who is responsible for carrying out the process. Rothstein notes that sensitive patient information may be manipulated without the

awareness and consent of the patient, potentially by individuals who lack relevant experience. Thus, there is not only ambiguity concerning who must complete the deidentification process, but also a lack of provisions regarding how these functions must be performed.

The utilization of personal health information for secondary uses must be examined from the point of view of elderly and chronically ill individuals. According to Darling (2007), the ecological systems theory represents how factors that are outside of an individual's control must be viewed from a “person process-context model”, whereby the individual is seen as a function of contextual factors. Due to their lengthy care history, elderly individuals suffering from chronic illnesses typically have extensive and detailed health records, which can be easily accessed by numerous health care providers and support staff. Consequently, it is necessary to seek consent from individuals when their personal health information is entered into a deidentified EHR database (Hoffman, 2010). According to Willison (2009), consent is vital because even though patient information may be removed of identifiers, the remaining data is still sufficiently rich in sensitive details such as medical procedures and dates of admission and discharge. Historically, secondary uses of personal health information for the purposes of quality improvement, risk management, health system amelioration, infection control and public health, have been permitted without additional patient consent.

Several steps need to be taken in order to ensure that chronically ill and elderly patients are aware of the secondary uses of their personal health information. According to Singleton and Wadsworth (2006), a tiered consent approach can be employed, which

gives a wider range of options to the patient. For instance, potential consent choices are: not using one's information for a certain type of research, requiring permission every time that information is used, requiring opt-in permission for a particular type of research, demanding notification with the option to opt-out, or permitting use without any notification. Moreover, information regarding consent can be presented to patients through a variety of media. For instance, Willison (2009) posited that information about the uses of one's health information can be printed in brochures and played as a DVD in hospitals or long term care institutions.

Although research employed through the use of EHRs can elicit public health benefits, patient comprehension and consent must be at the forefront of these research endeavors, particularly for chronically ill and elderly patients. According to Rausser et al. (2011), the political-economic lens emphasizes that a public policy is dependent on the distribution of power, which elicits winners and losers. The "winning" groups reap the benefits, while "losers" bear the burden of the policy. The lack of comprehensive consent options represents a misdistribution of power for patients. Indeed, patient groups will be forced to remain on the "periphery" of a policy, which is led by the powerful "center". This unequal distribution of power will elicit a hierarchy structure, whereby the center is authorized to make policy decisions and the peripheral groups remain subordinate.

Theme 4: lack of accountability due to multiple health information custodians.

A prevalent theme within the literature is a lack of accountability due to the use of an EHR system by multiple health information custodians. The main issues that arise within

the theme are: unclear guidelines regarding how personal health information must be handled when there are significant changes in the custodian's practice, a lack of consensus on how inappropriate EHR access or alterations can be addressed, as well as how to keep patients involved, particularly when a privacy breach has occurred.

A pan-Canadian electronic health record system will be able to interface patient information from a variety of health care encounters. According to Winkelman and Leonard (2004), chronically ill patients are typically managed by a team of clinical professionals such as physicians, nurses, therapists and social workers, with little communication amongst them. Clinicians that constitute a patient's care team will be able to easily access their health record and add content to it, making the record multi-voiced. Proponents of EHRs posit that such comprehensive access will elicit efficient patient-centered care. However, widespread access may also cause numerous privacy risks for patient groups such as elderly individuals suffering from chronic illnesses, particularly within an institutionalized care setting.

The Personal Health Information Protection Act outlines the responsibilities of health information custodians in relation to patient health information under their control. According to PHIPA, “a health information custodian shall take steps that are reasonable in the circumstances to ensure that personal health information in the custodian’s custody or control is protected against theft, loss and unauthorized use or disclosure and to ensure that the records containing the information are protected against unauthorized copying, modification or disposal,” 2004, section 2(12). However, there are certain circumstances where health information custodians may inadvertently compromise the privacy of a

patient.

Personal health information is at risk when there is a significant change in the practice of the health information custodian. For instance, such common practice alterations may be a practitioner's retirement, death, relocation or bankruptcy (Cavoukian, 2007). According to PHIPA, "If a health information custodian dies, the following person shall be deemed to be the health information custodian with respect to records of personal health information held by the deceased custodian until custody and control of the records, where applicable, passes to another person who is legally authorized to hold the records: 1. The estate trustee of the deceased custodian. 2. The person who has assumed responsibility for the administration of the deceased custodian's estate, if the estate does not have an estate trustee," 2004, section 3(12). However, the provincial act does not put forth guidelines for safe information transfer, nor does it consider who is best suited to receive a health information custodian's records in relation to privacy risks. Indeed, perhaps the individual who assumes responsibility for the records should be within the patients' direct circle of care, in order to limit unnecessary exposure of personal health information.

In addition to unforeseeable changes within a clinical practice, electronic health records may be subject to inappropriate access or alterations which could threaten patient privacy. According to Terry and Francis (2006), electronic health records can be erased, cut or pasted without an apparent trail, unlike paper records. Moreover, EHRs are easily searchable, and such searches can be rapidly employed. Furthermore, Hoffman (2010) posited that EHR systems typically require users to enter thorough and detailed

information. However, cut and paste capabilities allow clinicians to copy portions of prior notes unto current updates. This practice elicits information overload and can cause errors if the notes are not carefully edited. Furthermore, copying and pasting may cause clinicians to access prior portions of a patient's record which are not conducive for the particular care transaction, and could elicit threats to patient privacy. Indeed, the American Health Information Management Association reports that an average of 150 personnel has access to a patient's health record during a typical hospital stay (Hill & Powell, 2009).

There are several procedures which can be employed in order to prevent improper editing, accessing or circulation of electronic health records. Firstly, according to Terry and Francis (2006), there must be a method to ensure that entries are dated and signed by EHR users. As a result, penalties should be applied to unauthorized sharing of electronic user log-ins. Moreover, electronic health records should be correctable, but there must be a standardized method of noting that a correction has been made. Most significantly, records of unauthorized access must be maintained and patients should be notified if their record has been illegitimately accessed. According to Paquette and Ryan (2001), the ecological systems theory would hypothesize that technology has altered our society, but we have not gotten the necessary resources to provide safeguards to the damage done to our societal environment. Furthermore, according to Rausser et al. (2011), the political-economic lens emphasizes that power relationships need not be unilateral where the powerful center exercises power and influence over peripheral groups. Indeed, reciprocal or bilateral power relationships also exist. Thus, a transparent process must be established

in order to allow vulnerable patient groups such as elderly individuals who suffer from chronic illnesses, to comprehend the nature of privacy breaches and also have an opportunity to voice their concerns.

Theme 5: haphazard electronic health record malfunctions.

Privacy risks can be induced by haphazard electronic health record malfunctions. In this respect, the major issues are: system failures due to the coupling of components, display and navigation issues, as well as determining what level of access various clinicians should have.

Although electronic health records can organize personal health information and potentially facilitate care processes, errors within EHRs can elicit significant harm to patient privacy. According to Ludwick and Doucette (2009), health information technology systems are considered a lesser cause of errors, in relation to user processes. Although haphazard EHR errors are less common than those directly induced by system users, it is vital to consider their implication on patient privacy. According to Hoffman and Podgurski (2008), as the functionality of an EHR system becomes increasingly complex; risks to patient privacy drastically grow. More specifically, electronic health record systems display a significant degree of interdependence amongst their components. As a result, the failure of a single component can directly or indirectly impact the failure of another system component. Furthermore, such unanticipated interactions can even cause an electronic health record system to crash.

In addition to the interdependence of system components, the layout of an electronic health record system can also elicit errors. According to Hoffman and

Podgurski (2008), mistakes that cause breaches to patient privacy can result from system inflexibilities that impede a provider's ability to enter nonstandard data or order unlisted medication. Furthermore, usability issues, such as display and navigation inadequacies, can also cause errors that put patient privacy at risk. The source of these errors is largely rooted in an EHR system's failure to reflect clinician work flow.

Haphazard electronic health record system errors can potentially be overcome by restricting the level of access that various health information custodians have (Refer to the recommendations elicited under Theme 4). According to Rothstein (2007), certain health care providers need access to an individual's health record in order to perform treatment, but not all users need the same level of access. Consequently, health care providers and support staff should have access to the minimum necessary patient health information. According to Paquette and Ryan (2001), the ecological systems theory emphasizes that economic and political policies need to be established in order to support individuals existing in society. Furthermore, the ecological systems theory displays how the power and impact of proximal processes vary depending on the characteristics of the individual (Darling, 2007). Thus, haphazard EHR errors do not occur in isolation and are contingent on the user of the system. According to Rausser et al. (2011), the political-economic lens emphasizes that conflict between the public and special interest groups naturally arise during policy implementation. Although policies are meant to meet the public's needs, certain policies are manipulated by powerful groups who are concerned about their own self-interest. Due to budget cuts by the federal government (Refer to Theme 6), clinicians and healthcare support personnel must complete a higher number of

tasks within a minimal time frame. Thus, the complex and often hurried tasks that personnel may need to complete within an EHR may not be conducive to patient privacy. As a result, electronic health record systems must have the necessary technical protections in place in order to meet the privacy needs of vulnerable patient groups, such as the chronically ill and elderly.

Theme 6: the divergent interests of various stakeholders.

The federal government and EHR vendors are two influential stakeholders within EHR development. The major issues are: the lack of government oversight over Canada Health Infoway, the hindrance of EHR funding due to structural changes within the government, as well as the focus of EHR vendors on economic gain, rather than meeting security and quality standards.

The most influential stakeholder within the development of a pan-Canadian electronic health record system is the federal government. The primary goal of the federal government is to protect the health of Canadians, but do so in a cost-effective manner. However, from a political-economic perspective, the lack of government oversight and changes in the funding structure of EHRs can negatively impact the privacy of personal health information, particularly for vulnerable patient populations.

Over a decade ago, Canada's political leaders already identified the development of a pan-Canadian electronic health record system as a key healthcare priority. According to the Information Technology Association of Canada (2009), in 2001, the federal government established Canada Health Infoway, a not-for-profit, independent organization which would be responsible for strategically investing federal funds in an

EHR system. According to the Parliament of Canada (2012), Canada Health Infoway is neither a federal agency nor a crown corporation. Instead, Infoway is governed by a Board of Directors who are representatives of Canadian regions. The board also includes some private members.

There is a lack of federal government oversight within EHR funding. According to the Auditor General of Canada (2009), the federal government allocates a “lump sum” to Canada Health Infoway, who then determines how to fund provincial and territorial projects. As reported by Webster (2010), a study by McKinsey and Company projected that the total cost of implementing a national EHR system by 2017 would be approximately \$10-\$12 billion. An additional \$4 billion would be needed to procure appropriate health professionals.

In lieu of these projections, the federal government has allocated substantial funds to Canada Health Infoway. According to Webster and Kondro (2011), the government has invested approximately \$2.1 billion in the corporation. However, assessments of the corporation's progress reveal that it has not adequately addressed the needs of patients and health care providers, as Infoway has not met any of its eight self-established implementation targets. At the same time, according to the Auditor General of Canada (2009), the federal government has not fully developed a monitoring framework in order to oversee the funding and to monitor the organizations' progress. Indeed, a problematic disconnect exists between the government and Canada Health Infoway. The government is entrusting the organization to fund EHR projects, yet they are not effectively overseeing their fund allocation and project progress. Thus, the lack of government

oversight can elicit gaps in privacy protection, particularly as Infoway has not been made responsible for ensuring that EHR systems comply with jurisdictional privacy laws (Refer to Findings: Theme 2 for further details) (Auditor General of Canada, 2009).

In addition to a lack of government oversight, there has been a hindrance in the allocation of EHR funding due to structural changes within the federal government. According to the Parliament of Canada (2012), the Conservative Party maintained its minority position in the 2006 and 2008 elections, prior to becoming a majority government in 2011. The 2009 federal budget committed \$500 million for Canada Health Infoway, in order to encourage rapid EHR implementation. While developing the budget, the federal government was simultaneously realizing nearly \$87.2 million of savings from cutting funds to the Canadian Institute of Health Research, the Natural Sciences and Engineering Research Council of Canada and the Social Sciences and Humanities Research Council of Canada. In addition, the federal government has also been containing health care spending through reducing federal transfer payments to provinces and territories which support various Medicare and social programs.

In light of these drastic budget cuts, the federal government has been delaying and reducing funding for electronic health record development. Such funding cuts can influence the security capabilities of EHRs and negatively impact patient privacy. According to the Information Technology Association of Canada (2009), it is estimated that a national EHR will require an initial investment of \$350 for each Canadian. However, to date, that investment stands at \$50 per person. According to Webster (2010), in 2010, the federal government failed to release a \$500 million transfer to Canada Health

Infoway, which drastically slowed the next phase of the national EHR effort. This funding freeze thwarted the initiatives designed to improve physician uptake of EHRs. Indeed, in 2009, physician utilization was only at 37%, which placed Canada last among 11 nations such as Australia, Italy, The Netherlands, New Zealand and The United Kingdom. However, once the federal government actually provided the funding to Infoway, it diverted more than 30% of the money to other projects. Thus, Infoway did not receive the entirety of the allotted \$500 million.

In order to ensure effective EHR development, the federal government must closely oversee Infoway projects. Furthermore, the government must assess impending funding transfers based on need and deliver them in a timely manner. According to the Auditor General of Canada (2009), the government needs to further develop their monitoring approach in order to ensure that Infoway is complying with the funding agreements. Moreover, the government must monitor Infoway's activities on an ongoing basis, so that it can isolate and prevent non-compliance. According to Parliament of Canada (2012), public opinion polls constantly show the continuing importance of health care as a public policy issue for Canadians. As a result, while funding the EHR project, the government must make the health of Canadians their principal priority. Indeed, the Minister of Health, the Honorable Leona Aglukkaq stated that “an electronic health record system will improve the safety and accountability of the overall health care system” (Health Canada, 2009).

From a political-economic perspective, the role of health information vendors is highly influential in shaping imminent EHR implementation. Electronic health record

vendors will derive substantial economic profits from the adoption of EHR software by practitioners and health care institutions. Consequently, their primary interest is concerned with economic gain, rather than ensuring that the privacy of vulnerable groups such as the elderly and chronically ill is sufficiently protected. Consequently, EHR software companies view electronic health records as a mere technological tool, rather than an instrument which is strongly associated with one's privacy and related notions of autonomy and integrity.

As electronic health record vendors are primarily concerned with economic gain, they may not meet nation-wide implementation standards which convey expectations for preserving patient privacy. For instance, according to Hoffman and Podgurski (2008), EHR vendors may be against making their electronic health record platform interoperable. An interoperable EHR system makes it easier for providers to switch from one electronic health record platform to another. Without interoperability, the difficulty of transferring thousands of electronic health records between systems may deter providers from changing their EHR platform. Consequently, the establishment of an interoperable electronic health record system which meets national guidelines may be averted by EHR vendors, as it elicits an increase in cost and a substantial loss of profit.

In order to prevent electronic health record vendors from gaining a substantial amount of influence, stringent certification and approval processes of EHR systems must be established. At the outset of the approval process, applicants must submit project plans, software requirements and design, test plans and documentation for users and system administrators, to an appropriate regulatory agency (Hoffman & Podgurski,

2008). According to Barron (2011), within a typical business transaction, there is an inherent information asymmetry between the buyer and seller. More specifically, if the purchaser does not obtain the necessary information, then the power of the seller is enhanced, in whose hands the information is solely a commodity. As a result, according to Hoffman and Podgurski (2008), the material submitted by the seller should include information regarding how health care providers can customize the product in order to protect patient privacy. Furthermore, these instructions must be accompanied by a technical justification for why the customizations are considered safe for that particular health care environment.

In addition to thorough documentation, ongoing EHR system testing should be conducted. According to Hoffman and Podgurski (2008), prior to approval, electronic health record systems must be field tested for a period of at least six months under various conditions. Such testing will discern whether the software is conducive to a specific health care environment, and whether it is sufficient in protecting the privacy of distinct patient groups. Following an approval process, entities that assess electronic health record systems will need to be locally established in order to conduct constant oversight and re-assessment. Even after the approval process, EHR vendors must be made responsible to fix system defects, add additional privacy protection features or alter the system as needed. Following an approval process, information regarding the EHR software should be widely disseminated in order to allow health care institutions to make safe and informed choices. As a result, the regulatory agency must publish problem reports in print format or through a website, so that consumers can make an informed

choice.

On the whole, an EHR system must effectively balance the desires and needs of multiple stakeholders without infringing upon patient rights. According to Angst (2009), a “participative design” process should be implemented, where patients get an opportunity to express their distinct privacy views. As a result, rather than simply selling a product, EHR vendors must be held accountable for meeting the needs and concerns of patients. Indeed, according to Paquette and Ryan (2001), the ecological systems theory displays that individuals require ongoing community support as a means of attaining appropriate development. Consequently, patients, particularly those whom are elderly and suffering from chronic illnesses, need to be provided with opportunities for empowerment and control.

Discussion

As part of the major research project, a scoping review of published literature was conducted at the intersection of chronically ill seniors, privacy of health information and electronic health records (EHRs). Informed by the ecological systems theory and politic-economic lens, the review led to the identification of six themes: lack of interoperability between EHR systems, lack of integration between policies and procedures across jurisdictions, issues in secondary use of personal health information, lack of accountability in data ownership, haphazard malfunctions of EHRs and diverse interests of stakeholders. A detailed description and interpretation of these themes is presented in the previous section. This section is focused on establishing foci across the themes. These foci emerged as the inadequate inclusion and representation of chronically ill seniors and

the limited acknowledgement of the economic interests of EHR vendors. The section concludes with recommendations for privacy policy, health practice and research, with acknowledgement of the limitations of the review.

Patient Representatives in Electronic Health Record Systems

Even though the employed search strategy yielded 836 unique references, 116 of which appeared to be potentially relevant articles, only 11 references discussed chronic illnesses, while nine discussed both senior citizens and chronic illnesses. There is a substantial gap within current academic EHR literature to adequately represent the context and concerns of elderly and chronically ill individuals. Furthermore, it seems that pertinent knowledge is largely inaccessible to vulnerable patient groups, including the elderly and chronically ill, who may seek clarification regarding the privacy of their personal health information. From the ecological systems perspective, such disconnect between macro and micro systems can lead to unintended consequences. Moreover, as exhibited by the political-economic lens, power differentials can amplify the impact. Thus, the inclusion of chronically ill and elderly patients is vital for the success of a pan-Canadian EHR system. Elderly individuals suffering from cancer, arthritis or diabetes are a highly knowledgeable patient group who must be viewed as active stakeholders and given a voice within electronic health record development, particularly in regards to issues of privacy. This calls for a systematic approach towards patient empowerment.

Patient empowerment is an often sought goal in clinical practice, teaching and research. According to Salmon and Hall (2004), within patient empowerment, patients are expected to take control over their illness or treatments. Furthermore, the concept of

patient empowerment is contingent on the wider political and cultural emphasis on individual choice. However, as the employed scoping review highlighted, pertinent literature regarding information privacy within EHRs is largely circulated within the academic level and is inaccessible to vulnerable patient groups. However, due to their first hand experiences, the majority of chronically ill patients must be considered as experts in disease management, with insights that could complement and enhance those accessible to health care providers, policy makers and researchers (Leonard & Dalziel, 2011).

Patient empowerment can be cultivated through knowledge dissemination about privacy and consent, as well as knowledge control through variable access to personal health information (see Recommendations section). The Supreme Court of Canada has described informational privacy as “the right of the individual to determine for himself when, how and what extent he will release personal information about himself” (Ries, 2006). According to Rothstein (2012), privacy encompasses an individual's right to control access to and disclosure of their personal information through common law and legislation. However, as highlighted by Angst (2009), digitization of personal health information elicits strong feelings of vulnerability and the concern for privacy greatly varies amongst distinct individuals.

Current literature does not effectively establish a connection between privacy protection, the individual and society. The ecological system theory emphasizes that the individual is “active” and constantly interacts with their environment. Thus, it is imperative for knowledge regarding health information privacy and consent which is

proliferated within the academic level, to be widely disseminated to all patient groups.

Another means of attaining patient empowerment is when chronically ill and elderly individuals are given opportunities to control and restrict the transfer and uses of their personal health information. According to Paquette and Ryan (2001), the ecological systems theory emphasizes that as the outer layers change; they may negatively impact the inner layer by not meeting people's needs. However, individuals living with chronic conditions are already meeting their own needs through engaging in a high amount of “self-care”. Self-care is an inherent requirement of individuals with chronic illnesses since healthcare professionals may only interact with their patients for a few hours a year and for the rest of the time, patients must care for themselves (Canadian Academy of Health Sciences, 2010). As a result, chronically ill and elderly patients are highly capable of determining, monitoring and restricting the uses of their personal health information.

At the outset, chronically ill and elderly individuals must comprehend and concur with who constitutes their primary “circle of care”. According to Ries (2006), circle of care is a term used to describe those who are directly involved in providing health care and treatment for a patient. However, a patient's interpretation of a circle of care may differ from that of the health care provider. Consequently, the patient must be informed of the range of entities who are involved in their care and who share their personal health information. The patient and their primary health care provider must mutually agree upon who constitutes the patient's care team and how their personal information flows amongst the circle of care. Despite the advantages of such a process, it must be ascertained whether the health care system can handle it. More specifically, it must be determined

whether benefits to the patient outweigh clinicians' administrative responsibilities and time constraints.

Limited Acknowledgement of the Economic Interests of EHR Vendors

Through the application of a political-economic lens, it became evident that health information vendors are powerful stakeholders within EHR development. However, health information suppliers are only briefly mentioned in Ontario's Personal Health Information Protection Act. PHIPA states that “a person who provides goods or services for the purpose of enabling a health information custodian to use electronic means to collect, use, modify, retain or dispose of personal health information shall comply with the prescribed requirements if any”, 2004, section 10(4). Consequently, health information vendors are falsely pooled into the same category as health information custodians whom utilize patient information for care provision, rather than for economic gain.

Due to their powerful position and interest in economic gain, EHR vendors have the ability to thwart EHR development. However, those actions are rarely recognized or addressed. According to Mandl and Kohane (2012), EHR vendors are holding back innovation in the IT industry. More specifically, vendors are applying a business model to healthcare, as they avoid making their systems open and interoperable so that third-parties cannot utilize the application. Furthermore, EHR vendors prevent data from leaving the EHR system because once it leaves; other competing systems may handle the data better. This would result in a loss of customers for the vendor, which translates into a loss of profit.

The use of EHR consultants by health care organizations also emphasizes the limited acknowledgement of the economic interests of EHR vendors. According to Lynn (2009), EHR consultants are salesman disguised as consultants. Indeed, EHR vendors are the “realtors” of medical IT, as they sell software from vendors who pay them a substantial finder’s fee. Thus, health care organizations must be cautious when hiring a consultant to aide them with EHR implementation, as true consultants will have contact with numerous EHR vendors, rather than one.

The economic interests of EHR vendors can be acknowledged through the contract established between the vendor and the health care institution or provider. According to Fox and Schick (2011), an EHR contract must include adequate protections, safeguards and other rights reserved for the customers in order to address the asymmetry existing between the vendor and purchaser. Although it is common for such contracts to protect the vendor’s trade secrets and limit access to the software, it is less common to find similar protections for the purchaser’s information. Thus, the purchaser must establish obligations which limit the vendor’s use of the organization’s patient health information.

Recommendations

The scoping review identified six pertinent themes. Furthermore, two foci were established through cross-cutting of the themes. Based on the obtained themes and foci, recommendations for privacy policy, health practice and research were put forth.

Policy Level

Explicit recognition of the economic interest of vendors in PHIPA.

Although health information vendors must adhere to government standards, they are still largely independent authorities. Furthermore, their economic interests are rarely addressed (see Section 4.2). Consequently, future revisions of PHIPA should incorporate an entire section devoted to health information suppliers. The creation of a specific “EHR vendor” section would serve two functions. Firstly, it will ascribe long-term responsibility to health information vendors for developing and maintaining an EHR product which will not jeopardize patient privacy and secondly, it will make vulnerable patient groups more involved within EHR development.

Improved description of ‘circle of care’ in PHIPA

The provincial privacy policy is vague about who constitutes a patient’s circle of care and whether the patient has any say in the matter. According to Freedman (2004), PHIPA permits health information to be managed on the basis of implied consent within the circle of a patient's care-giving team. Thus, PHIPA allows health information custodians to exchange patient health information on implied, rather than expressed consent, as long as the exchanged information assists in health care provision. However, the role of the patient within their medical circle of care is unclear. Future revisions of PHIPA must incorporate a clause which articulates how patients can approve which health information providers constitute their care circle. Furthermore, such a clause can describe a patient's right in tracking their personal health information flows within their care team.

Patient control over the release of personal health information.

In addition to determining who is involved in their care, chronically ill and elderly patients must be given opportunities to control the amount of information in their record which is accessible to any particular health care provider. According to Rothstein (2010), patients can place limits on their information and make it visible based on the role of the health care provider, date of prior encounters, type of health care provided, diagnoses or procedures. For instance, a patient can provide a physical therapist with less information access than their primary physician. Furthermore, a patient can potentially block older records or only make psychiatric records only available through additional permission.

Lockbox or “secure envelope” provisions can also allow chronically ill and elderly patients to control their personal health information. According to Terry and Francis (2006), lockbox provisions allow patients to specify whether certain records from their provider or from particular visits, be kept out of any electronic record system. Although the exclusion of certain medical information may compromise the accurateness and completeness of an EHR, more responsibility would be placed on the patient to control their personal health information flows. As more responsibility would be placed in the hands of vulnerable patient groups, this would elicit an increase in patient empowerment.

Practice Level

Resources for localized interpretation of PHIPA.

The provincial legislation leaves specific rules regarding electronic health records to be developed in regulations. PHIPA posits that: “a health information custodian that

uses electronic means to collect, use, modify, disclose, retain or dispose of personal health information shall comply with the prescribed requirements, if any, 2004, section 10(3). Consequently, PHIPA leaves ample room for healthcare institutions to develop their own regulations regarding personal health information. The potential disconnect between the overarching provincial policy and distinct institutions can threaten patient privacy, particularly for chronically ill and elderly individuals. Thus, there should be sufficient resources provided for local health institutions such as hospitals and long-term care facilities, to effectively translate PHIPA within their specific care context and comply with it accordingly.

Consent description in patient forms.

The Personal Health Information Protection Act highlights specific elements required for patient consent. Indeed, “the consent (a) must be a consent of the individual, (b) must be knowledgeable, (c) must relate to the information; and (d) must not be obtained through deception or coercion, 2004, section 3(18). On the whole, PHIPA's requirements for consent are broad as the act covers consent to medical treatment, as well as to collecting, using and disclosing information provided by the patient for the purposes of treatment.

Although PHIPA covers a wide range of consent options, hospitals and privately-practicing physicians typically use a single form in order to obtain consent for both treatment and for the collection, use and/or disclosure of personal health information (Prokopieva, 2005). Consequently, there is a disconnect between the broad notion of consent highlighted within PHIPA and its' limited conception by health care providers. As

a result, future revisions of the act must differentiate between conceptions and actual applications of consent. Thus, patient groups such as the chronically ill and elderly patients must comprehend these disparities, particularly when solely agreeing to the sharing of their personal health information, rather than to undergoing treatment.

Inclusive methodology.

Within the impending EHR environment, chronically ill and elderly individuals must be given more information about the uses of their personal health information. According to Ries (2006), individuals typically maintain an ongoing interest in their health information after it has been collected and is in the hands of health care providers. As a result, patients must be made aware of all potential trade-offs that may exist between the maintenance of their privacy and the delivery of coordinated, safe, and effective health care (Rothstein, 2010). Furthermore, patients should be given an opportunity to opt out from sharing their personal health information (Ries, 2006).

Research Level

Participatory research approaches.

In light of the imminent pan-Canadian EHR system, it is imperative for future research to employ participatory approaches. According to Cornwall and Jewkes (1995), conventional health research tends to elicit “knowledge for understanding” while participatory research focuses on “knowledge for action”. Indeed, participatory research emphasizes a “bottom-up” approach with a focus on local needs and perspectives. Involving chronically ill seniors as participants in research can enhance the effectiveness of EHRs, as well as elicit financial and time savings. The study conducted by Kim et al.

(2009) provides a pertinent example of a participatory approach to research. Within the study, a PHR system was deployed within a federally funded housing facility for low-income and elderly residents over a 33-month period. Nursing students and researchers aided the participants with entering and managing their health information within the PHR. Use and user satisfaction were assessed through participant meetings, questionnaire surveys and system logs.

Inclusion of specific chronic diseases.

As the scoping review demonstrated, there is limited literature regarding cancer, diabetes and arthritis in relation to EHR and health information privacy for seniors. These chronic illnesses disproportionately impact senior citizens. Indeed, only 20 out of 50 located sources discussed chronic illnesses. From the 20 sources which discussed chronic illnesses, one discussed cancer, four discussed diabetes, five discussed diabetes and cancer, and only four discussed diabetes, cancer and arthritis. Consequently, future reports and studies must focus on the distinct chronic illnesses which are common amongst seniors.

Personal health records.

The use and maintenance of a personal health record (PHR) can provide a means for patients to monitor and control their personal health information. According to Gibbons (2011), a PHR is an internet or USB-based tool which may be linked with existing electronic health records and can allow patients to access, input, change, coordinate and control their health information. Unlike electronic health records, PHRs are almost exclusively accessed and controlled by the patients themselves. The most

profound impact of personal health records is their ability to encourage patients to become more active in managing their personal health information and care (Angst & Agarwal, 2006). According to Snowdon et al. (2011), in light of the impending pan-Canadian EHR system, PHRs can help in shifting the culture of Canadian health care from a paternalistic approach where the “doctor knows best” to a culture where patients are inspired to take a lead role in their health. Patient health records can empower chronically ill and elderly patients to manage their information and determine whether they feel comfortable seeking additional support. Consequently, PHRs can provide a means of closing the existent literature gap which was highlighted by the employed scoping review, through providing vulnerable patient groups the means to attain empowerment.

Limitations

The scoping review presented here is the first of its kind to review current knowledge on whether the impending electronic health record system can adequately protect the privacy of chronically ill seniors in relation to Ontario's Personal Health Information Protection Act, or whether alternative measures need to be implemented prior to the establishment of a nation-wide EHR system. Unlike traditional scoping reviews, this review incorporated Bronfenbrenner's ecological systems theory and the political-economic lens, as a means of analyzing the themes that have emerged from the literature. Furthermore, the ecological systems theory and the political-economic lens aided in linking the needs of chronically ill and elderly individuals to the structure and function of the impending pan-Canadian EHR system, as well as to the encompassing

political-economic environment.

Despite the advantages of this paper, there are also several noteworthy limitations. Firstly, a single reviewer (student researcher: CZ) was responsible for screening the titles and abstracts against the established inclusion and exclusion criteria. Furthermore, the same reviewer also independently reviewed the full-text articles or reports. Thus, as a single reviewer located the included literature, there was no effective means through which to address ambiguities or indecisiveness. Future applications of this study should include a minimum of two reviewers, as they can resolve disagreements and ambiguities through discussion. Moreover, despite a focus on literature pertaining to Canada, there is an absence of French literature altogether. Future applications of this study should obtain more source from European countries, as the majority of the articles and reports were from the United States (n=25) and Canada (n=22), and only a few originated from Western Europe (n=3).

Appendices

Appendix 1: Search of Electronic data bases and Journals

Database	Results (n)	Included (n)
Scholars Portal	120	9
Jstor	20	0
	65	0
CBCA Complete	1	0
PubMed	5	2
Proquest	1	0
	82	1
Medline (Ovid)	6	2
PsycInfo	1	0
Scopus	7	2
CINAHL	51	2
REHABDATA	0	0
Nursing and Allied Health Source	0	0
Social Science Research Network	37	11
Canadian Periodicals Index	0	0
Sociological Abstracts	0	0
Social Work Abstracts	14	0
Ebsco	182	7
Canadian Health Research Collection	33	0
Journal	Results (n)	Included (n)
Intellectual Property Law Journal	1	1
Health Law Journal	126	2
Canadian Journal of Law & Technology	84	1
Total	836	40

Total number of included sources: 50

Appendix 2: Detailed Breakdown of Reviewed Sources

Type of Sources Reviewed

Discussion paper: 27

Research study: 9

-*Case Study*: 2

-*Pretest-Posttest Design*: 1

-*Survey (Descriptive Design)*: 3

-*Randomized Control Trial*: 1

-*Longitudinal (Retrospective)*: 1

-*Focus Group*: 1

Information guide: 2

Information guide and recommendation report: 7

Commentary: 2

Literature review: 3

Population Studied:

Senior citizens: 0

Chronically ill: 11

-*Cancer*: 1

-*Diabetes*: 4

-*Arthritis*: 0

- *Diabetes and arthritis*: 0

-*Diabetes and cancer*: 5

-*Cancer and arthritis*:

-*Cancer, diabetes and arthritis*: 4

Both senior citizens and chronically ill: 9

Country or Regions studied:

Canada: 22

United States: 25

Western Europe: 3

Other: 0

Year of Publication:

2012: 2

2011: 7

2010: 8

2009: 12

2008: 5

2007: 6

2006: 6

2005: 0

2004: 4

Appendix 3: Example of Literature Charting

Author, Year, Setting, Type of Source	Key Aims and Objectives	Methods	Relevant Findings	Critical Assessment
Adam et al, 2007, USA, Discussion paper	To propose ways through which identifying patient information can be protected when information is utilized for research	n/a	Encryption procedures are proposed which can be employed by healthcare institutions in order to de-identify patient information from different sources	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? no
Angst & Agarwal, 2006, USA, Research Study	To examine attitude persuasion regarding EHRs when concerns about information privacy are present in patients	Randomized Control Trial Web-based Survey	-Privacy concerns are a pivotal factor in influencing an individual's beliefs about the use of EHRs -Individuals' attitudes can be modified in a favorable way towards EHRs -Individuals with high privacy concerns are less prone to persuasion about EHRs. Thus, must clearly communicate assurances about security. -Study revealed strong, visceral feelings that people have about the privacy of their EHR -Privacy risks are greatest threat to successful EHR rollout	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? no
Angst & Agarwal, 2004, USA, Research Study	To study the adoption and use of PHRs from the patient's perspective	Web-based survey	-PHRs can elicit improved patient-physician communication, elicit patient understanding of their health conditions and increase patient involvement within their care -analysis of survey data revealed that perceived patient value is related to patients' intention to use system in future -Patients derive three values from PHRs: 1) desire for structure, organization and	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? yes

			<p>compliance, 2) desire for connectedness with one's health care provider and 3) desire for convenience and empowerment</p> <p>-Adoption of PHRs is correlated with value that individuals perceive to gain from them</p>	
Angst, 2009, USA, Discussion Paper	Drawing on a theoretical base of social dilemmas, the paper investigates whether individuals should consider their health information a public good	n/a	<p>-There is a delicate balance between acting in self-interest or acting in the interest of society as a whole</p> <p>-Participative design must be used to develop EHR programs in order to balance needs of patients and stakeholders</p> <p>-Having better information available to users will lead to better care and outcomes and reduced costs</p> <p>-Healthcare consumers have a right to be educated about the pros and cons of such a system</p>	<p>1. Were elderly citizens discussed? no</p> <p>2. Were chronic illnesses discussed? no</p>
Balka et al, 2007, Canada, Discussion Paper	To reveal the broader social and political implications that surround the implementation of a Canadian EHR system, and not just the "minor" technical issues raised by Romanow report	n/a	<p>-A wider and critical view of the implementation of information technologies is absent from the report</p> <p>- Report uncritically accepts that EHRs will meet goals of healthcare</p> <p>-Technology cannot be viewed as neutral, must reflect on its' political, economic, social and cultural implications</p>	<p>1. Were elderly citizens discussed? no</p> <p>2. Were chronic illnesses discussed? no</p>
Ball, 2007, USA, Discussion Paper	To assess whether PHRs can empower patients and help ameliorate care provision	Interviews with experts, assessment of existing PHR systems	<p>-PHRs must be implemented in phases</p> <p>-PHRs must be tailored for patients, as they are not homogenous</p> <p>-Need collaboration across sectors when implementing PHRs, especially for privacy</p> <p>-US can learn from other nations who progressed with PHRs- Canada, New</p>	<p>1. Were elderly citizens discussed? no</p> <p>2. Were chronic illnesses discussed? yes</p>

			Zealand, UK, Australia, Germany	
Baron, 2011, USA, Discussion Paper	To determine whether patients can construe health information within an EHR as a "property right"	n/a	-Misleading to think of information control as property rights -"property" cannot tell us how much control individuals should have over their personal health information -Concept of property does not capture the complexity of EHRs	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? no
Bath, 2008, UK, Discussion Paper	Paper discusses how ehealth initiatives actively involve users in the design, development, implementation and evaluation phases	n/a	-Health informatics requires particular consideration as an emerging discipline within information science -Success of ehealth initiatives depends on active involvement of users in the design, development, implementation and evaluation of initiatives	1. Were elderly citizens discussed? yes 2. Were chronic illnesses discussed? Yes
Canada Health Infoway, 2010, Canada, Information Guide and Recommendation Report	Document provides information on appropriate trans-jurisdictional health information flows	n/a	Document discusses: -the Pan-Canadian common understandings to support trans-jurisdictional disclosures of EHR information within Canada -Trans-jurisdictional disclosures of EHR information for secondary uses -Accountability for information governance in the EHR	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? no
Canadian Academy of Health Sciences, 2010, Canada, Information Guide and Recommendation Report	To determine how to improve care for chronically ill individuals within Canada	n/a	-Chronically ill patients must be engaged in their own care -Care must be of high quality and coordinated, numerous services must be offered -All accomplishments must be evaluated -Need for coordination between the federal and provincial government	1. Were elderly citizens discussed? yes 2. Were chronic illnesses discussed? yes
Canadian Cancer Society, 2012, Canada,	To provide information regarding	n/a	Report provides following data: -Incidence of mortality	1. Were elderly citizens

Information Guide	incidence, mortality and other measures of cancer burden for the most common types of cancer, presented by age, sex, time period and province/territory		by cancer type -Incidence of mortality by geographic region -Incidence of mortality by age, sex -Time trends in incidence and mortality	discussed? yes 2. Were chronic illnesses discussed? Yes
Canadian Institute for Health Information, 2011, Canada, Research Study	To examine the reported experiences of Canadian seniors being treated for chronic illnesses in primary care settings	Surveys distributed	-Healthy seniors require less healthcare -Seniors taking a larger number of prescription medication were at a greater risk of suffering from side effects that require medical attention -Gaps exist in preventative and collaborative care for seniors	1. Were elderly citizens discussed? yes 2. Were chronic illnesses discussed? yes
Cavoukian, 2007, Canada, Information Guide and Recommendation Report	To elicit guidelines which focus on compliance with the requirements under PHIPA and adherence to privacy and access best practices with respect to managing recording containing personal health information	n/a	Document discusses: -Who is the appropriate health information custodian in the event of a change in practice -What obligations are imposed on custodians by PHIPA in the event of a change in practice -Best practices in the event of a change in practice	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? no
Cavoukian & Rossos, 2009, Canada, Information Guide and Recommendation Report	Discusses why privacy is important in the delivery of healthcare and outlines the general obligations that health care providers have to protect personal health information within EHRs	n/a	Document discusses: -Why privacy is significant -Obligation of health care providers to protect patient privacy -How to transition from paper-based to an electronic record system -How to safely utilize electronic patient information -How to manage and dispose of old paper records -How to manage privacy breaches	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? no
Curtis et al, 2011, Canada, Research Study (Case	Case study discusses how Sunnybrook	Review of surveys and the qualitative feedback received from patients	-Sunnybrook's PHR represents one of the leading examples of PHR	1. Were elderly citizens

Study)	Hospital's PHR program effectively responds to development challenges on four fronts: patient and clinician adoption, feature design and usability improvements, multi-site integration and service enabling for peers	and providers	<p>success in Canada, when patients and providers are seeking flexible, cost-effective and personalized means to deliver healthcare information</p> <p>-The PHR elicited strong patient and physician satisfaction</p> <p>-PHR set the stage for an expansion of the service to multiple institutional and community providers which will ensure the promise of a true continuity of a care record</p>	<p>discussed? no</p> <p>2. Were chronic illnesses discussed? no</p>
Daglish & Archer, 2009, Canada, Discussion Paper	To address design and architectural issues of PHR systems and focus on privacy and security issues which must be addressed if PHRs are to become generally acceptable to consumers	n/a	<p>-There are significant benefits to PHR use, but there are also architecturally specific risks to their adoption that must be considered</p> <p>-An integrated PHR is able to take its content from many sources, which reflects the reality of the patient experience, with many providers and institutions providing care over time</p> <p>-Integrated PHR is best suited to move along with the technological evolution</p> <p>-Content of PHRs needs to conform to an accepted and interoperable set of standards</p> <p>-There needs to be sufficient funding and resources in providing the necessary infrastructure to bring PHRs to Canadian consumers</p>	<p>1. Were elderly citizens discussed? no</p> <p>2. Were chronic illnesses discussed? no</p>
D'Agostino & Woodward, 2009, Canada, Discussion Paper	To determine the ideal scope of EHRs, clarification of EHR ownership, control and access issues	n/a	<p>-Numerous legal complexities surround EHRs- issues of privacy, confidentiality and security will arise with the implementation of a nation-wide EHR system</p> <p>-Intellectual property</p>	<p>1. Were elderly citizens discussed? no</p> <p>2. Were chronic illnesses</p>

			<p>protection must be applied to EHRs</p> <ul style="list-style-type: none"> -The debate/uncertainty of who owns and controls which aspects of EHRs will hinder the development of EHRs and may threaten patient privacy -Needs of each stakeholder must be weighed and addressed prior to implementing EHRs -Governance model needs to be established, which would remove legal ambiguities for all parties involved 	<p>discussed? no</p>
Freedman, 2004, Canada, Discussion Paper	To assess whether privacy legislation incorporates the role of information technology and information management providers	n/a	<ul style="list-style-type: none"> -Certain aspects of PHIPA need to be altered in order to instill confidence and encourage the use of electronic means of personal health information management -Information management providers need to be considered within PHIPA -Due to lack of inclusion, PHIPA leaves an impression that the Ministry has not yet developed a clear position on the use of EHRs and safe and secure access 	<p>1. Were elderly citizens discussed? no</p> <p>2. Were chronic illnesses discussed? no</p>
Harris et al, 2010, Canada, Research Study (Correlational Study)	To establish a validated electronic medical record definition for diabetes	A retrospective cohort was constructed	<ul style="list-style-type: none"> -Impending development of a diabetes registry holds potential for contributing to and enhancing chronic disease registries with the goal of improving disease management and health outcomes -Diabetes definitions must be developed and validated within the impending EHR environment 	<p>1. Were elderly citizens discussed? no</p> <p>2. Were chronic illnesses discussed? yes</p>
Hill & Powell, 2009, USA,	To discuss how the national electronic	n/a	-ehealth can address USA's healthcare crisis	1. Were elderly

Discussion Paper	healthcare network is under-appreciated and under-exploited, and faces several formidable barriers to implementation		-However, ehealth faces several barriers that only a comprehensive, national agenda can rectify -The national agenda should address the legal, operational and cost asymmetry barriers in a holistic and integrated fashion	citizens discussed? no 2. Were chronic illnesses discussed? no
Hoffman, 2010, USA, Commentary	Argues that while the privacy and autonomy of patients is significant, databases of deidentified EHRs can make valuable contributions to medical knowledge	n/a	-There is immense value in research involving deidentified EHRs and biological samples -These databases would enable researchers to conduct comprehensive observational studies based on patients' clinical experience	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? no
Hoffman, 2010, USA, Discussion Paper	Paper explores how the advent of EHRs will impact the workplace, in addition to healthcare	n/a	-EHRs may pose risks and challenges for the workplace, particularly through disclosures of sensitive health information which may lead to privacy concerns and discrimination -These concerns must be addressed through changes to existent privacy legislation and parallel state laws -Technological advances and appropriate federal	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? no
Hoffman & Podgurski, 2008, USA, Discussion Paper	Paper analyzes EHR systems from both a legal and technical perspective and examines how law can serve as a tool to promote health information technology	n/a	-EHRs must adhere to best software engineering and medical informatics practices -Regulatory intervention is needed in order to ensure that those goals are met -Like the regulation of food, devices and drugs, federal government must regulate EHR systems because their dependability and usability is vital to patient welfare -EHR software must undergo stringent assessment/certification processes	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? no
Kaelber et al,	Existing PHR	100 citations reviewed	-Existing knowledge	1. Were

2008, USA, Literature Review	specific literature was reviewed and divided into seven categories	and grouped into seven categories	base that underpins PHRs is limited, and many issues remain unresolved -4 categories identified through the literature which represent opportunities for future research: 1) evaluation of PHR functions, 2) adoption and attitudes of health care providers and patients towards PHRs, 3) PHR-related privacy and security and 4) Substantial financial support must be committed to PHR research and evaluation	elderly citizens discussed? no 2. Were chronic illnesses discussed? no
Kierkegaard, 2011, Denmark, Discussion Paper	To assess the privacy concerns posed by a centralized supernational central EHR server across Europe	n/a	-EHRs can allow clinicians to easily access patient records. However, they can lead to an increase in the amount of information collected, sorted, filtered, transferred or retained -Diversity of health systems across Europe is a stumbling block for enabling the deployment of cross-border EHRs -Privacy risks must be mitigated prior to widespread EHR implementation	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? no
Kim et al, 2009, USA, Research Study	To assess the use and utility of PHRs in low-income elderly populations	Web-based PHR system in a federally funded housing facility for low-income elderly residents. Use and user satisfaction were assessed through logs, surveys and group meetings	-Findings suggest that those that benefit the most from a PHR system, may be least able to use it -Disparities in access to and use of computers, the internet and PHRs may exacerbate health care inequality in the future	1. Were elderly citizens discussed? yes 2. Were chronic illnesses discussed? yes
Leonard et al, 2008, Canada, Discussion paper	Paper explores how providing chronically ill patients with direct access to their personal health information can elicit substantial savings in health care	n/a	-By allowing chronically ill patients to play an active role in managing their care, a significant strain will be removed from the healthcare system -Chronically ill patients need a health recording system specifically	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? yes

			<p>designed and implemented for them, with essential decision-support capabilities built in</p> <p>-As chronically ill patients experience changes in their health status, they will continually demand for ways to consume information and improve self-management</p> <p>-Thus, chronically ill patients must be recognized as powerful active participants with the ability to drive change and the adoption of PHRs</p>	
Leonard & Dalziel, 2011, Canada, Discussion Paper	The paper elaborates on the cost-effectiveness of ehealth solutions and the need to evaluate the return on investment as is done routinely with all major expenditures	Technology Adoption Criteria in Health (TEACH) model and Wagner's Chronic Disease Management Model are applied	<p>-The benefits of ehealth solutions outweigh the costs, but only when applied to chronically ill patients</p> <p>-Once an effective ehealth system is developed for chronically ill patients, it can be applied to all patients and stakeholders</p>	<p>1. Were elderly citizens discussed? no</p> <p>2. Were chronic illnesses discussed? yes</p>
Ludwick & Doucette, 2009, Canada, Literature Review	Purpose of review is to identify the current state of knowledge about health information system adoption in primary care	6 databases, 27 journal websites, 20 websites from grey sources, 9 websites from medical colleges and professional associations and 22 government/commission websites were searched	<p>-Health information systems are seen as solutions to the widening health care supply-demand gap</p> <p>-Health information system implementations are not simple and instead, they may cause significant cultural and organizational upheaval</p> <p>-Physicians and other health care providers must be thoroughly prepared for impending changes</p> <p>-Governments may need to coach physicians through implementations by providing leadership training, project management and product training services</p>	<p>1. Were elderly citizens discussed? yes</p> <p>2. Were chronic illnesses discussed? yes</p>

			-Governments should provide physicians with necessary financial support	
Maloney & Wright, 2009, USA, Discussion Paper	To determine the features of commercially available USB-based PHRs and compares the recommendations made by certification committees	n/a	-The data elements, cost, features and compatibility of currently available USB PHRs may not be adequate for consumers' safety and medical needs -Future research and PHR development should be geared towards supporting clinical decision support, interoperability with current EMR systems, and enhanced patient-clinician interaction	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? yes
Mirolla, 2004, Canada, Information Guide and Recommendation Report	To assess the impact of chronic disease within Canada	n/a	-Chronic disease has high economic impact on Canada, particularly due to loss of productivity -Chronic conditions are becoming more common within seniors -Interventions are necessary in order to provide effective and ongoing treatment for individuals suffering from chronic disease -Interventions should also focus on prevention, particularly with aging populations	1. Were elderly citizens discussed? yes 2. Were chronic illnesses discussed? yes
Office of the Auditor General of Ontario, 2009, Canada, Information Guide	Audit is assessing whether the Ministry of Health and Long-Term Care and eHealth Ontario have adequate systems and procedures in place to help ensure that EHRs for Ontario are being implemented in cost-effective and progressive manner	n/a	-Recommendations regarding how EHRs can be rapidly and cost-effectively developed within Ontario are put forth -Problematic and costly use and procurement of consultants by the Ministry and eHealth are highlighted	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? no
Peregrin, 2009, USA, Discussion Paper	To assess the tools typically incorporated	n/a	-Health care providers are often using basic technology (i.e. email,	1. Were elderly citizens

	within electronic medical-record keeping programs, such as EHRs, PHRs		internet, etc) but concept of medical record keeping is new and misunderstood -Health care providers must network with one another and seek information, as they have a professional responsibility -Health information technology can aide in monitoring, education and counseling	discussed? no 2. Were chronic illnesses discussed? no
Prokopieva, 2006, Canada, Discussion Paper	To examine the implications of the new federal and Ontario personal data protection legislation for physicians and public hospitals. Paper also explores whether the new legislation will contribute to the protection of patient privacy	n/a	-PHIPA's obligations resemble those imposed by PIPEDA. However, PHIPA' sobligations are more closely aligned with the needs and traditions of the medical profession than PIPEDA -PHIPA also provides more workable provisions on consent -Both PHIPA and PIPEDA take technological developments into account -Author concludes that PHIPA better meets the needs of Ontario's health care sector	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? no
Ries, 2006, Canada, Discussion Paper	Paper documents recent changes in provincial and federal consent legislation in Canada, in comparison to UK and Australia. Paper considers whether current privacy laws are sufficient in protecting patient privacy	n/a	-Application of legal rules and ethical imperatives regarding patient informed consent to collection, use and disclosure of one's personal health information is not advancing as rapidly as needed -It is largely impossible to obtain true informed consent from a patient regarding uses and disclosures of their PHI, because patient must understand how their information will be used throughout the entire EHR system -Providers must provide basic information about a patient's specific	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? no

			<p>information and technical information about the EHR system</p> <ul style="list-style-type: none"> -There is a grey area between consent to de-identified personal health information, unclear how much control a patient has over that -There is a lack of national uniformity in regards to legislative regimes that apply to collection, use and disclosure of PHI -Privacy protection must be incorporated into policies and guidelines. Should not be seen as a barrier, but as “protection” 	
Rivkin-Haas, 2011, USA, Discussion Paper	<p>Paper examines the existing privacy law standards applicable to medical records in US and Canada and then considers whether the current privacy framework offers patients adequate protection against these new privacy concerns</p>	n/a	<ul style="list-style-type: none"> -The laws in both US and Canada recognize the need to balance individuals’ privacy with the common good -Like many rights, privacy is not absolute. Courts struggle to address the needs of society without entirely compromising those of the individual -What constitutes a violation of privacy and what harms occur as a result of such violations, is not static. Technology is re-shaping how countries view privacy and continually present new dilemmas -Canada’s approach to the privacy problem can be applied to US. I.e. Canada established a Privacy Commission and Privacy Commissioner 	<p>1. Were elderly citizens discussed? no</p> <p>2. Were chronic illnesses discussed? no</p>
Rothstein, 2012, USA, Discussion Paper	<p>Discusses issues involved in wider access to segmented health information, the inadequacy of current laws, and the need to</p>	n/a	<ul style="list-style-type: none"> -Lack of patient privacy impact the patient, as well as quality of public healthcare -Segmentation of personal health information isn’t necessarily a single 	<p>1. Were elderly citizens discussed? no</p> <p>2. Were chronic illnesses</p>

	implement wide ranging privacy policies before segmentation systems are adopted		<p>solution, it is a starting point for more targeted limitations on health information disclosures</p> <ul style="list-style-type: none"> -Segmentation is difficult to implement, particularly in emergency access, clinical decision support and messaging to other health care providers -Is users access is not limited, it will elicit a step backwards from current privacy protection and cause individuals to engage in "self-help defensive measures" to protect their privacy 	discussed? no
Rothstein, 2007, USA, Discussion paper	Paper reviews the key privacy issues that must be resolved before widespread EHR adoption and the interoperable networks of the NHIN	n/a	<ul style="list-style-type: none"> -NHS privacy efforts have fallen behind its technology-development efforts, but they are being overwhelmed by health information technology system creation and the implementation of the private sector -Need effective privacy policies to be established, or patient information will be carried by new electronic networks with little or no regulation of its many potential uses 	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? no
Rothstein, 2010, USA, Discussion Paper	To examine whether the process of de-identifying information for health research is sufficient in protecting the privacy of individuals, particularly marginalized groups	n/a	<ul style="list-style-type: none"> -Research involving de-identified information needs clear consent processes and must ensure that patients comprehend them -Must create interoperable standards across jurisdictions and healthcare institutions around how de-identified information will be used -Misconceptions exist around how such information is used within research, and they must be cleared up 	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? no
Rothstein, 2010,	Explores the	n/a	-Physicians and patients	1. Were

USA, Discussion Paper	patient-provider relationship in relation to the development of health information technology		need a new Hippocratic bargain -Physicians and other health care professionals must respect their patients' choices regarding information disclosures, to preserve the confidentiality of the information entrusted to them and to disclose information only in accordance with the law and prior agreements with their patients	elderly citizens discussed? no 2. Were chronic illnesses discussed? no
Rothstein & Talbot, 2006, USA, Commentary	To explore potential mechanisms to prevent the disclosure of sensitive health information with no clinical usefulness when third parties compel individuals to disclose their health information	n/a	-Contextual access criteria can enable holders of individual health information to limit the scope of disclosures for non-medical purposes based on the type of information needed by the third party. Thus, employers and insurers can only access limited portions of an individual's record which only pertain to their query -Must create a system which grants authorized access only to relevant personal health information while keeping other information confidential -If such a system is not developed, individuals suffering from certain conditions may limit their disclosure to their health care providers and loved ones, which negatively impacts their health status	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? yes
Schneider, 2010, USA, Research Study (Case Study)	Outlines the types of EHRs and their uses, barriers to implementation, and issues patients should be aware of when contemplating compiling their own PHRs	Case study of the Veterans Healthcare Administration PHR	-The VHA PHR has provided a safe, secure PHR for patients that exceeds all standards and certification -The PHR displays relevant content and an ease of navigation -Every year, it is enhanced with new	1. Were elderly citizens discussed? yes 2. Were chronic illnesses discussed? yes

			<p>elements, additional content and features to make it user-friendly</p> <ul style="list-style-type: none"> -The PHR serves as a model to patients and health care organizations as a cost effective user-friendly method for tracking one's health history 	
Singleton & Wadsworth, 2006, UK, Discussion Paper	Paper discusses consent in relation to secondary uses of medical records in research	n/a	<ul style="list-style-type: none"> -The legal and ethical aspects of consent must be simplified for researchers and public through: <ul style="list-style-type: none"> -Clear guidance on good practice in the management of research data -Clear legal definitions of anonymisation and consent that are practicable and recognize the needs to balance the needs of the individuals and the community -Ways to manage risks of confidentiality must be established -Role of large scale medical research databases in healthcare research must be clarified -Ways to harmonize and gain consent for medical research must be clarified 	<p>1. Were elderly citizens discussed? no</p> <p>2. Were chronic illnesses discussed? no</p>
Snowdon et al, 2011, Canada, Information guide and recommendation report	Report discusses how baby boomers and the elderly, particularly those with chronic illnesses can become engaged within healthcare	n/a	<p>Five key recommendations are made:</p> <ul style="list-style-type: none"> -Engage consumers directly in the healthcare system -Use new technologies to improve the communication flow among the health care team -Develop new technologies and software to support consumer engagement in access the health care system -Re-design health care 	<p>1. Were elderly citizens discussed? yes</p> <p>2. Were chronic illnesses discussed? yes</p>

			<p>services to reach out to consumers and support health and wellness care at home</p> <p>-Use new technologies to achieve real system integration</p>	
Terry & Francis, 2006, USA, Discussion Paper	The article addresses whether an EHR system can operate within a framework of ethically and practically satisfactory confidentiality, privacy and security	n/a	<p>-Personal health data must be limited within a patient's circle of care and shared solely on a "need to know" basis</p> <p>-Several privacy protecting strategies are explored, such as: consent options, lockbox provisions and "opt in" processes</p> <p>-Privacy of health information is examined from a legal perspective, particularly in reference to several legal cases</p> <p>-Lockbox/secure envelope provisions are explored as a potential strategy to elicit increased patient control over personal health information and to prevent the occurrence of privacy breaches</p> <p>-Cannot simply focus on the technical aspects of EHRs. Must examine the interests of patients in relation to their health care providers, in order to incorporate an autonomy-based and comprehensive privacy EHR structure</p>	<p>1. Were elderly citizens discussed? no</p> <p>2. Were chronic illnesses discussed? yes</p>
Terry, 2008, USA, Discussion Paper	Paper assesses whether PHRs can adequately protect patient privacy	n/a	<p>-PHRs pose distinct and in some situations, enhanced risks, requiring a similarly elevated level of legal protection as for EHRs</p> <p>-Legal model needs to be re-worked, so that there is sufficient legal protection for PHRs</p>	<p>1. Were elderly citizens discussed? no</p> <p>2. Were chronic illnesses discussed? no</p>
Weber et al, 2007, USA, Research study	Study employed an electronic registry derived from a fully integrated	Best practice measures were created for diabetes. The measurement tool was	-Diabetes improved significantly in response to a multifaceted intervention featuring	1. Were elderly citizens discussed?

	EHR as the cornerstone of an intervention to improve compliance with recommended diabetes performance measures in an integrated practice network	used as a part of a multifaceted intervention to improve physician performance in diabetes care. Changes in performance were tracked monthly over one year	the use of an EHR-derived registry in an integrated delivery system -Significant increases were seen in all measures of diabetes, such as vaccination for pneumococcal disease and influenza and blood pressure control	no 2. Were chronic illnesses discussed? yes
Willison, 2009, Canada, Information guide and recommendation report	Paper examines current challenges in governing research use of health information and potential approaches to addressing these issues in the context of the common interoperable EHR	n/a	-Observational health research and privacy protection have both been framed as public goods -Technical changes must come together in order to make fundamental changes to both observation research and to protection of confidentiality and security. These include: the advent of the interoperable EHR, the development of research platforms through registries and biobanks, etc -Governance and infrastructure changes must be completed soon, in order to avoid insufficient and inefficient "ad hoc" amendments to governance over research	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? no
Winkelman & Leonard, 2004, Canada, Literature Review	To determine whether current EHR structure allows for patient use for self-directed disease management. As well, relationship between medical record structure and patient utilization of health care information systems was explored	Systematic review of literature from a critical perspective	-Traditional information systems research and development methods may not entirely capture social issues that arise when expanding access of EHR systems to patients -Future studies must include action research	1. Were elderly citizens discussed? no 2. Were chronic illnesses discussed? yes
Wright et al, 2009, USA,	To assess the proportion of	Conducted a mail survey of a stratified random	-Many physician practices were able to	1. Were elderly

Research Study	physician practices that can construct registries of patients with specific diagnoses, laboratory results, or medications and to determine the relationship between EHR usage and the ability to perform registry functions	sample of physician practices. 71% response rate	generate registries, but this is not universal -Practices with EHRs are more likely to carry out registry functions -Since practices need registries to perform broad based quality improvement, they should consider the adoption of EHRs with built-in registry functionality	citizens discussed? no 2. Were chronic illnesses discussed? yes
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References

- Anderson, S., Allen, P., Peckham, S., & Goodwin, N. (2008). Asking the right questions: scoping studies in the commissioning of research on the organisation and delivery of health services. *Health Research Policy and Systems, 6*. Retrieved from <http://www.health-policy-systems.com/content/7/1/7>
- Angst, C. M., & Agarwal, R. (2006). Overcoming personal barriers to adoption when technology enables information to be available to others. *Proceedings of 27th International Conference on Information Systems, Milwaukee, WI*. Retrieved from http://papers.ssrn.com/sol3/papers.cfm?abstract_id=922075
- Angst, C. M. (2009). Protect my privacy of the common-good? The social dilemma of the opt-in versus opt-out decision related to electronic health information exchanges. *Journal of Business Ethics, 90*, 169-178.
- Armstrong, P., Armstrong, H., & Coburn, D. (2001). *Unhealthy Times: Political Economy Perspectives on Health and Care in Canada*. Toronto: Oxford University Press.
- Armstrong, R., Hall, B. J., Doyle, J., & Waters, E. (2011). Cochrane update 'scoping the scope' of a Cochrane review. *Journal of Public Health, 33*, 147-150.
- Arskey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology, 8*, 19-32.
- Auditor General of Canada. (2009). Report of the auditor general of Canada to the House of Commons. chapter 4: electronic health records. Retrieved from http://www.oag-bvg.ca/internet/English/parl_oag_200911_04_e_33205.html

- Balka, E., Rodje, K., & Bush, C. G. (2007). Rose-coloured glasses: the discourse on information technology in the Romanow report. *Canadian Journal of Communication, 32*, 475-494.
- Baron, J. B. (2011). Property as control: the case of information. *Michigan Telecommunications and Technology Law Review, 20*. Retrieved from http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1931605
- Bronfenbrenner, U. (1979). *The ecology of human development: experiments by nature and design*. Cambridge, MA: Harvard University Press
- Canadian Academy of Health Sciences. (2010). Transforming care for Canadians with chronic health conditions. Retrieved from <http://www.caahs-acss.ca/transforming-care-for-canadians-with-chronic-health-conditions-put-people-first-expect-the-best-manage-for-results-2/>
- Canadian Cancer Society. (2012). Canadian cancer statistics 2012. Retrieved from https://www.cancer.ca/Canada-wide/About%20cancer/Cancer%20statistics.aspx?sc_lang=EN
- Canada Health Infoway. (2011). About Canada Health Infoway. Retrieved from <https://www.infoway-inforoute.ca/about-infoway>
- Canada Health Infoway. (2010, June 30). Privacy and EHR information flows in Canada: common understandings of the pan-Canadian health information privacy group. Retrieved from https://www2.infoway-inforoute.ca/Admin/Upload/Dev/Document/Common_Understandings_Privacy_EN.pdf
- Canadian Institute for Health Information. (2011). Seniors and the health care system:

what is the impact of multiple chronic conditions? Retrieved from <https://secure.cihi.ca/estore/productSeries.htm?pc=PCC548>

Cavoukian, A. (2007). How to avoid abandoned records: guidelines on the treatment of personal health information, in the event of a change in practice. Retrieved from <http://www.privacybydesign.ca/content/uploads/2009/05/abandonedrec-guidelines.pdf>

Cavoukian, A., & Rossos, P. G. (2009). Personal health information: a practical tool for physicians transitioning from paper-based records to electronic health records. Retrieved from <http://www.ipc.on.ca/images/Resources/phipa-toolforphysicians.pdf>

Cornwall, A., & Jewkes, R. (1995). What is participatory research? *Social Science & Medicine*, *41*, 1667-1676.

Daglish, D., & Archer, N. (2009). Electronic personal health record systems: a brief review of privacy, security, and architectural issues. *2009 World Congress on Privacy, Security, Trust and the Management of e-Business*. Retrieved from <http://dl.acm.org/citation.cfm?id=1674449>

D'Agostino, G., & Woodward, D. A. (2010). Diagnosing our health records in the digital world: towards a legal governance model for the electronic health record in Canada. *Intellectual Property Law Journal*, *22*, 127- 154.

Darling, N. (2007). Ecological systems theory: the person in the center of the circles. *Research in Human Development*, *4*, 203-217.

Dixon-Woods, M., Agarwal, S., Jones, D., Young, B., & Sutton, A. (2005). Synthesizing

- qualitative and quantitative evidence: a review of possible methods. *Journal of Health Services Research & Policy*, 10, 45-53.
- eHealth Ontario. (2011). About eHealth Ontario. Retrieved from <http://www.ehealthontario.on.ca/about/index.asp>
- Freedman, B. (2004). The regulation of information technology and information management providers under the Personal Health Information Protection Act, 2004. *Information and Technology Law*, 8, 22-25.
- Gibbons, M. C. (2011). Use of health information technology among racial and ethnic underserved communities. *Perspectives in Health Information Management*, 8. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3035830/>
- Government of Ontario. (2004, November 1). Personal Health Information Protection Act. Retrieved from http://www.e-laws.gov.on.ca/html/statues/english/elaws_statues_04p03_e.htm
- Government of Saskatchewan. (2003, September 1). The Health Information Protection Act. Retrieved from <http://www.qp.gov.sk.ca/documents/english/Statutes/Statutes/H0-021.pdf>
- Harsanyi, J. (1967). Games with incomplete information played by Bayesian players. *Management Science*, 14, 159-182.
- Health Canada. (2009). Government of Canada support electronic health record system that will save time and lives. Retrieved from http://www.hc-sc.gc.ca/ahc-asc/media/nr-cp/_2009/2009_14-eng.php
- Hill, J. W., & Powell, P. (2009). The national health care crisis: is ehealth a key solution?

Business Horizons, 52, 265-277.

Hoffman, S. (2010). Electronic health records and research: privacy versus scientific priorities. *Health Privacy in Research*, 10, 19-20.

Hoffman, S. (2010). Employing ehealth: the impact of electronic health records on the workplace. *Kansas Journal of Law & Public Policy*, 19, 409-432.

Hoffman, S., & Podgurski, A. (2008). Finding a cure: the case for regulation and oversight of electronic health record system. *Harvard Journal of Law & Technology*, 22. Retrieved from <http://jolt.harvard.edu/articles/pdf/v22/22HarvJLTech103.pdf>

Howitt, D., & Cramer, D. (2007). *Introduction to Research Methods in Psychology: second edition*. Retrieved from http://wps.pearsoned.co.uk/ema_uk_he_howitt_resmethpsy_2/77/19810/5071470.cw/index.html

Information Technology Association of Canada. (2009). The issue: ITAC eHealth. Retrieved from http://www.itac.ca/uploads/pdf/The_Issue-ITAC_eHealth-November_2009.pdf

Kim, E., Stolyar, A., Lober, W. B., Herbaugh, A. L., Shinstrom, S. E., Zierler, B. K., Soh, C. B., & Kim, Y. Challenges to using an electronic personal health record by a low-income elderly population. *Journal of Medical Internet Research*. Retrieved from <http://www.jmir.org/2009/4/e44/>

Leonard, K.J., Dalziel, S. (2011). How and when ehealth is a good investment for patients managing chronic disease. *Health care Management Forum*, 24, 122-128.

Leonard, K. J., Casselman, M., & Wiljer, D. (2008). Who will demand access to their

- personal health record: a focus on the users of health services and what they want. *Healthcare Quarterly*, 11, 92-96.
- Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: advancing the methodology. *Implementation Science*, 5. Retrieved from <http://www.Implementationscience.com/content/5/1/69>
- Ludwick., D. A., & Doucette, J. (2009). Adopting electronic medical records in primary care: lessons learned from health information systems implementation experience in seven countries. *International Journal of Medical Informatics*, 78, 22-31.
- Mandl, K. (2012). HIT expert contends that EHR vendors are curbing innovation. Retrieved from <http://www.healthcare-informatics.com/article/hit-expert-contends-ehr-vendors-are-curbing-innovation-part-2>
- Mirolla, M. (2004). The cost of chronic disease in Canada. Retrieved from <http://www.gpiatlantic.org/pdf/health/chroniccanada.pdf>
- Nash, J. (1951). Non-cooperative games. *Annals of Mathematics*, 54, 286-295.
- Office of the Auditor General of Ontario. (2009). Ontario's electronic health record initiative. Retrieved from http://www.auditor.on.ca/en/reports_en/ehealth_en.pdf
- Paquette, D., & Ryan, J. (2001). Bronfenbrenner's ecological systems theory. Retrieved from www.nl.edu/paquetteryanwebquest.pdf
- Parliament of Canada. (2012). The health of Canadians- the federal role: final report. Retrieved from <http://www.parl.gc.ca/Content/SEN/Committee/372/soci/rep/repoct02vol6part4-e.htm>
- Prokopieva, E. (2005). New federal and provincial personal information protection

- legislation and its impact on physicians and public hospitals. *Canadian Journal of Law and Technology*, 4, 45-57.
- Rausser, G. C., Swinnen, J., & Zusman, P. (2011). *Political Power and Economic Policy: Theory, Analysis, and Empirical Applications*. New York: Cambridge University Press
- Ries, N. (2006). Patient privacy in a wired (and wireless) world: approaches to consent in the context of electronic health records. *Alberta Law Review*, 43, 681-712.
- Rivkin-Haas, E. (2011). Electronic medical records and the challenge to privacy: how the United States and Canada are responding. *Hastings International and Comparative Law Review*, 34, 177-201.
- Rothstein, M. A. (2012). Access to sensitive information in segmented electronic health records. *Journal of Law, Medicine & Ethics*, 40. Retrieved from <http://www.ssrn.com/abstract=2066120>
- Rothstein, M. A. (2007). Health privacy in the electronic age. *Journal of Legal Medicine*, 28. Retrieved from <http://www.ncbi.nlm.gov/pmc/articles/PMC3086539/>
- Rothstein, M. A. (2010). Is deidentification sufficient to protect health privacy in research? *The American Journal of Bioethics*, 10, 3-11.
- Rothstein, M. A., & Talbott, M. K. (2006). Compelled disclosure of health information: protecting against the greatest threat to privacy. *The Journal of the American Medical Association*, 295, 2882-2885.
- Rothstein, M. A. (2010). The Hippocratic bargain and health information technology.

- Journal of Law, Medicine & Ethics*, 38. Retrieved from
http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1589671
- Salmon, P., & Hall, G. M. (2004). Patient empowerment or the emperor's new clothes. *Journal of the Royal Society of Medicine*, 97, 53-56.
- Singleton, P., & Wadsworth, M. (2006). Consent for the use of personal medical data in research. *BMJ*, 333, 255-258.
- Snowdon, R. N., Shell, J., & Leitch, K. K. (2011). Transforming Canadian health care through consumer engagement: the key to quality and system innovation. Retrieved from <http://sites.ivey.ca/healthinnovation/files/2011/02/Consumer-Engagement-White-Paper-Final.pdf>
- Statistics Canada. (2011). Canada's population estimates: age and sex. Retrieved from <http://www.statcan.gc.ca/daily-quotidien/110928/dq110928a-eng.htm>
- Statistics Canada. (2010). Health status: arthritis. Retrieved from <http://www.statcan.gc.ca/pub/82-229-x/2009001/status/art-eng.htm>
- Statistics Canada. (2010). Health status: diabetes. Retrieved from <http://www.statcan.gc.ca/pub/82-229-x/2009001/status/dia-eng.htm>
- Terry, N. P., & Francis, L. P. (2006). Ensuring the privacy and confidentiality of electronic health records. *University of Illinois Law Review*, 2007, 681-735.
- The Cochrane Collaboration. (2012). Cochrane Reviews. Retrieved from <http://www.cochrane.org/cochrane-reviews>
- Webster, P. C. (2010). Canada's electronic health records initiative stalled by federal funding freeze. *Canadian Medical Association Journal*, 182, 247-248.

- Webster, P. C., & Kondro, W. (2011). Audit concludes Infoway missed program targets. *Canadian Medical Association Journal, 183*, 893-894.
- Willison, D. J. (2009). Use of data from the electronic health record for health research-current governance challenges and potential approaches. Retrieved from http://www.priv.gc.ca/nformation/pub/ehr_200903_e.cfm
- Winkelman, W. J., & Leonard, K. J. (2004). Overcoming structural constraints to patient utilization of electronic medical records: a critical review and proposal for an evaluation framework. *Journal of the American Medical Infomatics Association, 11*, 151-161.

