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Perceptions of online information privacy among individuals with Parkinson's Disease

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Perceptions of online information privacy among individuals with Parkinson's Disease

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Perceptions of online information privacy among individuals with Parkinson's Disease

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Abstract and Keywords

The growth in Internet use for health care is paralleled by the increase in chronic health conditions such as Parkinson's disease (PD). This study explores the perceptions of online privacy held by individuals with PD. Ten individuals with PD participated in hour-long, semi-structured, in-person interviews. Analysis of the transcripts yielded four major themes regarding participant perceptions: (1) online information privacy, including discussions of private information, exceptions, and anonymity; (2) media, family, and friends as sources of knowledge about online information safety; (3) reasons for privacy concerns, including physical vulnerability, the lack of 'people' on the Internet, and attitudes toward privacy and disclosure; and, (4) non-privacy related reasons for non-use of Internet resources. Highlighted aspects of participant perceptions include: lack of awareness concerning privacy legislation and online PD communities, the perceived value of online resources as factual not supportive, and inability to form bonds of trust in online relationships.

Keywords: privacy, Parkinson's disease, perception, perceptions of privacy, confidentiality, private information, seniors, elderly, online, Internet

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CHAPTER 1: INTRODUCTION

Within Canada, 80% of adults aged 16 or older made use of the Internet for personal reasons in 2009; this represents a 12% increase since 2005 (Statistics Canada, 2009; Statistics Canada, 2005). Of this group, 70% used the Internet to search for health or medical information, making health information-seeking the fifth most common online activity among Canadian adults (Statistics Canada, 2009). According to the PEW Internet and American Life project, 55% of Americans who have access to the Internet have used the web to find health information; 21 million of these adults suggested that online information influenced their health choices (Rainie & Fox, 2000). In effect, the Internet has created new opportunities, services, resources and tools for health care clients and consumers.

The term Web 2.0 refers to the development of information and data-rich, 'collective intelligence' Internet applications, most commonly characterized by user generated content (Hughes, Joshi & Wareham, 2008; Murugeson, 2007). Collective intelligence refers to the ability of Web 2.0 applications to develop organically, for example, through hyperlinking, which creates networks of connections through the web. The online bookseller Amazon© is sometimes cited as an example of Web 2.0, where the collective rankings, reviews, and knowledge contributions of online shoppers are constantly monitored, accumulated and added to the information available on the website (O'Reilly, 2005). Perhaps more aptly, Wikipedia is an example of Web 2.0 application that interactively allows users to collaboratively generate constantly evolving content (Murugeson, 2007). Medicine 2.0 or Health 2.0 refers to health resources founded on the application of Web 2.0 tools. A recent systematic review suggests that the concept of Medicine 2.0 or Health 2.0 centres around consumers' abilities to collaboratively use social networking, Internet based health resources, and for health professionals to manage their patients' personal health issues (Van De Belt, Engelen, Berben, & Schoonhoven, 2010).The range of abilities associated with the use of Web 2.0 tools for health care include online information access and increased contact between health care clients, health care providers, and researchers (Eysenbach, 2008; Hughes, Joshi & Wareham, 2008). This represents a core shift in the way that health information is created and disseminated, and the manner in which health care is provided (Eysenbach, 2008; Hughes, Joshi & Wareham, 2008). Consumers can now access medical and health information, health resources, and health professionals in ways that, before Web 2.0, would not have been possible (Hughes, Joshi & Wareham, 2008).

This growth in Internet use for health care is paralleled by the increased prevalence of chronic health conditions such as cardiovascular disease, diabetes, and Parkinson's disease (PD) (Public Health Agency of Canada, 2010; Public Health Agency of Canada, 2009a; Public Health Agency of Canada, 2009b). These conditions tend to be long-lasting, incurable, and are often degenerative medical conditions that require management rather than curative regimes of care. The Canadian Chronic Disease Surveillance System (CCDSS), together with the Public Health Agency of Canada (PHAC) have reported an increased incidence of cardiovascular disease and an estimated 25% increase in incidences of hypertension and diabetes in Canadians between 2006 and 2012, even while mortality rates are decreasing (Public Health Agency of Canada, 2010; Public Health Agency of Canada, 2009a; Public Health Agency of Canada, 2009b). Recent estimates indicate that Parkinson's Disease (PD), with an average age of onset of about 60 years, affects over 100,000 Canadians, and is expected to increase in numbers as the baby boomer generation ages (Public Health Agency of Canada, 2009a; Parkinson Society Canada). Parkinson's disease is a chronic, progressive, and incurable motor system disease that is characterized by a shuffling gait, persistent tremors, slow and slurred speech, and lack of balance. There are no confirmed causes of PD, although certain genes have been linked with PD occurrence and it has been hypothesized that non-genetic risk factors, such as environment, play a role in PD development (Davie, 2008; de Lau & Breteler, 2006; Guttman, Kish, and Furukawa, 2003).

The rise of Health 2.0 has changed the ways through which individuals with a chronic disease can access information and support. The use of Internet applications (e.g., Google), and participation in health-based social networks or online communities (e.g., Facebook, PatientsLikeMe), for example, allows patients to research and discuss medications, potential treatments and symptoms of health conditions in a relatively accessible manner (Eysenbach, 2008; Hughes, Joshi & Wareham, 2008; Van De Belt, Engelen, Berben, & Schoonhoven, 2010). Since chronic disease entails a life-long process, patients are expected to participate in the understanding and management of their illness; the Internet therefore becomes an increasingly important resource in gaining, gathering and sharing information (Wagner, Bare, Bundorf & Singer, 2004).

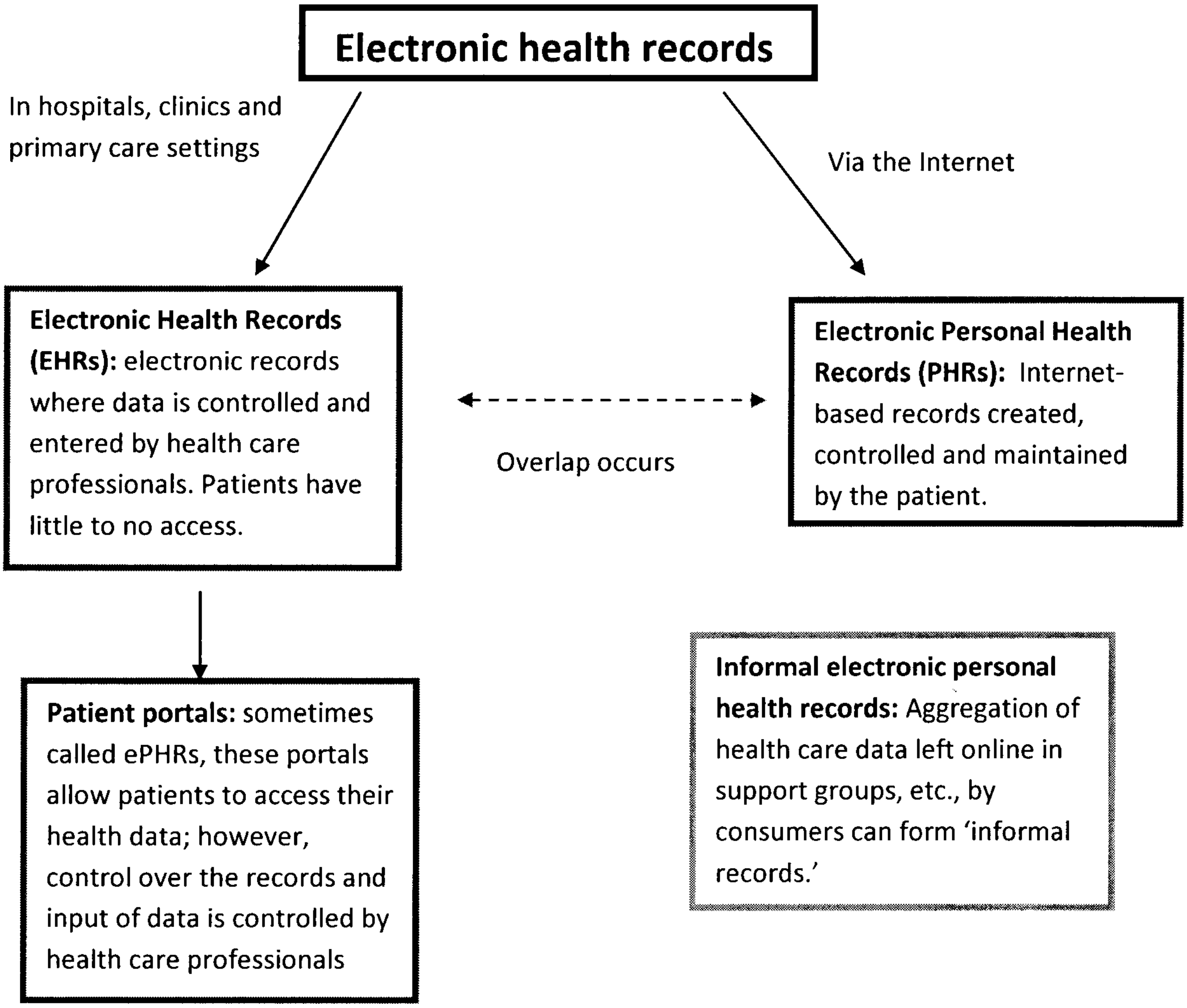
The introduction and use of health care technology, however, creates new concerns over information privacy, confidentiality and security. Of Canadian adults who made use of the Internet, almost one-third identified themselves as being 'very concerned' about their privacy while online (Statistics Canada, 2009). Similarly, 89% of adult online health information seekers in the U.S. were concerned about information privacy (Rainie & Fox, 2000). Web 2.0 technology enables health care consumers to access online information, but also to contribute their personal information which is then retained online (e.g., archived discussion within health support networks and health information sites) (Van De Belt, Engelen, Berben, & Schoonhoven, 2010; O'Reilly, 2005). In essence, the Internet has become an informal data repository or personal health record of consumer's health information. Insidiously and without intention, consumer contributed online health information, aggregated in a piecemeal fashion, could potentially create a reasonably comprehensive record of an individual's health care profile (King, 1996; Willison, 2003). For the purposes of this research, these informal records shall be referred to as *informal electronic personal health records*, to distinguish them from other, formal electronic health records. These different forms of electronic health records, and their relationship to one another, can be seen in Figure 1.

The International Standards Organization (ISO) defines an electronic health record (EHR) as a "... repository of patient data in digital form, stored and exchanged securely, and accessible by multiple authorized users... It contains retrospective, concurrent and prospective information and its primary purpose is to support continuing, efficient and quality integrated health care." (Hayrinen, Saranto & Nykanen, 2008, p.293). EHR applications typically fall into one of four application types (as seen in Figure 1) and will be discussed in this review. The "electronic health record," a category that includes electronic *patient* and *medical* records, includes the data resulting from professional medical care, and is primarily medical office, hospital, or health clinic based (Hayrinen, Saranto & Nykanen, 2008).

In contrast to the EHR, the personal health record (PHR) is controlled by the patient and is typically available through Internet based providers such as myPHR, InstantHealthHistory, or Microsoft Health Vault (Hayrinen, Saranto & Nykanen, 2008). In Ontario the Personal Health Information Privacy Act (2004) also defines a class of records as "mixed records", noting that "personal health information includes identifying information that is not personal health information... but that is contained in a record that contains personal health information." This includes demographic information about the age, race, gender, location and other personal details of a patient or consumer. For the purposes of this study, both PHRs and EHRs shall be included in the term 'formal health record' as both require the active, knowing creation of a specific health-centred record.

In contrast to these formalized records, 'informal health records' constitute an aggregate of personal health information that exists on the Internet but were created piecemeal, without the purposeful intent of creating or contributing to any documented accounting of personal health status. The growth of online social networking and other Internet resources has generated the creation of informal personal health records from the personal data on the internet. Acquisti and Gross, who investigated the privacy of personal information on social networking sites suggest that "sensitive personal data hide in plain sight amid transactions that rely on their privacy yet require their unhindered circulation" (2009, p.10975). Not surprising, but concerning, was the accuracy in which the investigators were able to predict individuals' Social Security numbers, based on their personal but publicly available online information (Acquisti & Gross, 2009).

Although personal information privacy is currently regulated federally by the Personal Information Protection and Electronic Documents Act (PIPEDA) in Canada, the rise of Web 2.0 applications and online social networking has caused concerns about the efficacy of PIPEDA in the rapidly changing Internet age (PIPEDA, 2000; Frazier, 2004; Racicot, 2005). The trend towards Internet-based healthcare has created a new set of privacy concerns, perceptions, and worries, which we have yet to fully explore or understand. For example, there is limited literature on how individuals who use Web 2.0 applications (e.g., participation in online health communities) understand and perceive the existing information privacy regulations. Yet, in order to fully leverage the health care potential of Web 2.0 applications and to create a positive environment for further innovation in the evolution of electronic health care, an investigation of consumers' perceptions of personal health information privacy concerns is warranted.



Electronic Health Records (EHRs): electronic records where data is controlled and entered by health care professionals. Patients have little to no access.

Electronic Personal Health Records (PHRs): Internet-based records created, controlled and maintained by the patient.

Patient portals: sometimes called ePHRs, these portals allow patients to access their health data; however, control over the records and input of data is controlled by health care professionals

Informal electronic personal health records: Aggregation of health care data left online in support groups, etc., by consumers can form 'informal records.'

Fig. 1: Different forms of electronic-based health records. 'Formal' records are EHRs, PHRs, and Patient Portals, where health care consumers aim to create a comprehensive record of health care matters and treatment. Overlap between PHRs and EHRs comes from possible 'merged' systems, where the PHR is linked to a hospital- or clinic- based EHR.

Research Purpose

The purpose of this research was to explore the perceptions of health information privacy among individuals who are diagnosed with Parkinson's disease (PD). This research addressed the perceived privacy and confidentiality of personal health information among individuals who are diagnosed with PD, specifically investigating participant's perceptions of personal information privacy and confidentiality with regards to the Internet and Internet-based PD communities and resources. PD is characteristic of many chronic illnesses, and serves as an exemplar of some of the key issues required to support people with chronic and complex health care needs (Lloyd, 2000). With the population of Canada aging, PD represents the health care needs of Canadian seniors, as well as exemplifying the needs of those who have a chronic disease that requires life-long self care and management (Lloyd, 2000). PD was therefore chosen as the focus of this study due to being a prime example of the challenges and needs of those with chronic disease that Canadian electronic health care systems could optimally assist.

Management of chronic disease often necessitates life changes due to physical disability or impairment as well as isolation compounded by the effects of aging. Online resources (e.g., information and support communities) can offer rich possibilities in assisting those with PD in managing their health condition from the comfort of their own home, in a time of their choosing. Investigating and addressing the privacy perceptions and concerns of individuals with PD when using the internet is therefore critical in realizing those possibilities.

CHAPTER 2: LITERATURE REVIEW

2.1 Parkinson's Disease in Canada

The Canadian Institute of Health Information (CIHI) has reported that 4.3% of the individuals in complex continuing care in Ontario have a diagnosis of PD (CIHI, 2006). Although young onset PD can appear in individuals in their 30s or 40s, the average age of onset is 60 years old with 'significant disability' occurring approximately 10 to 15 years after diagnosis (Parkinson Society Canada, 2010). PD is a neurodegenerative disease caused by progressive damage to dopamine-producing nerve cells, resulting in a loss of motor co-ordination, tremors, rigidity and impaired balance. The progression of the disease typically follows a four stage process, the latter two of which are characterized by the onset of physical symptoms in the individual and the emergence of neuronal cell degeneration into new areas of the brain (Davie, 2008).

A diagnosis of PD is based on manifested symptoms, one of which is tremor at rest, a symptom that is used to distinguish PD from essential tremor, when tremor only occurs during action (Guttman, Kish, & Furukawa, 2003). Individuals with PD typically present with bradykinesia, which causes an individual to slow down during everyday actions, and causes shuffling gait and an expressionless face (Guttman, Kish, & Furukawa, 2003; Lees, Hardy, & Revesz, 2009). Muscle rigidity, changes in posture, shuffling walk, swallowing problems, slow speech, changes in writing, and dementia can also manifest as PD symptoms (Davie, 2008; Guttman, Kish, & Furukawa, 2003; Lees, Hardy, & Revesz, 2009). Current treatment for Parkinson's disease is symptomatic, often involving increasing amounts of medications such as levodopa (e.g., to manage involuntary tremors, bradykinesia) as the illness progresses (Guttman, Kish, & Furukawa, 2003; Lees, Hardy, & Revesz, 2009). There are no current neuro-protective medications or therapies available to treat PD (Davy, 2008; Lees, Hardy, & Revesz, 2009; Stanley-Hermanns & Engebretson, 2010). Typically, after several years of treatment, individuals with PD often exhibit a 'wearing-off' phenomenon, wherein the efficacy of the prescribed medication(s) (e.g. levodopa) decreases; in addition, motor complications can arise from levodopa-induced dyskinesias. The most common complication is called peak-dose dyskinesia, which refers to involuntary movements in the head, trunk, and limbs of the individual (Davie, 2008; Jankovic, 2005). The development of dyskinesias is dependent on the duration of levodopa treatment, with women possibly being more likely to develop dyskinesias (Schrag & Quinn, 2000). Lifespan for individuals with PD is reduced, with death occurring at a mean of 15 years after diagnosis (Lees, Hardy & Revesz, 2009). Men are approximately 1.5 times more likely to present with PD than are women, although these findings are currently disputed, and may only be true in the population of individuals over 70 who live in Western countries (Lees, Hardy, & Revesz, 2009; Twelves, Perkins, & Counsell, 2003). In one study, out of 253 individuals with PD, women on average showed a later onset than men, by 2.1 years and better motor abilities, but men demonstrated a lower level of dyskinesias (Haaxma et al., 2006).

Young and old onset PD

Typically, over 90% of individuals with PD are over the age of 60 (Guttman, Kish, & Furukawa, 2003). Young onset PD is generally acknowledged as PD that occurs in individuals under the age of 40 or 45, estimated to occur in approximately 5 to 10% of PD cases (Boxall, 1994; Lees, Hardy, & Revesz, 2009). Individuals with young-onset PD demonstrate a shorter life expectancy than individuals with older-onset PD, and those diagnosed between ages 25 and 39 experience a mean life expectancy of 38 years, or an average age at death of 71 years (Ishihara, Cheesbrough, Brayne, & Schrag, 2007). Individuals with young-onset PD are also more likely to experience dyskinesias or motor complications related to PD drug treatment, as well as compulsive and harmful abuse of dopamininergic drugs (Evans, Lawrence, Potts, Appel, & Lee, 2005; Sossi, de la Fuente-Fernandez, Schulzer, Adams, & Stoessl, 2006). As PD and its symptoms can make working difficult, many individuals with young-onset PD may struggle to retain work and end up retiring early due to PD related difficulties (Banks & Lawrence, 2006).

2.2 Social support, online communities, and PD 'Online'

Social relationships and peer support are foundational aspects of health promotion. Social support refers to all the interpersonal resources that a person can draw on for material and emotional support, and includes both community support (e.g., neighbourhood support) and personal support from friends and family (Moak & Agrawal, 2010). Within the health promotion literature, the creation of supportive environments has been identified in both the Ottawa Charter for Health Promotion (WHO, 1986) and the Adelaide Recommendation of Healthy Public Policy (WHO, 1988) as key to health promotion activity. Social support is critical not only to treatment of chronic diseases but also to the prevention of them, and it forms an important part of preventive healthcare and the creation of 'healthy environments' (Berkman, 1995; Dennis, 2003; Public Health Agency of Canada, 2003; WHO, 1998).

Social support groups can be formal (e.g., hospital-based, health professional-led support groups) or informal (e.g., interpersonal support from family and friends) (Goodwin et al, 2001). Supportive-expressive group therapy is a type of formal support group where members are encouraged to discuss how their lives, thoughts, and worries are affected by their illness (Goodwin et al, 2001). This type of social support has been shown to decrease perceived pain in participants and lessen distress (Goodwin et al, 2001). There is evidence linking lower levels of social support and social interaction to higher mortality rates in adult patients with diabetes (Ciechanowski et al., 2010). Support group participation among informal caregivers of individuals with chronic disease was an important contributor to their increased sense of empowerment (Alberto & Joyner, 2008; Hajek, Humphrey & McRobbie, 2010; Lo, 2010; Miller & Crawford, 2010).

Increased financial strain on the Canadian health care system has resulted in shorter hospital stays, less accessible health care, and increased expectations of patient self-care (Dennis, 2003). These elements have contributed to the increased need for and use of patient-based social networks (Dennis, 2003). In-person support groups have positively supported chronic disease management (e.g. obesity, chronic obstructive pulmonary disease (COPD) and mental illnesses) through goal achievement, enhanced social functioning, decreased hospital admissions, and increased optimism and self-care (Alberto & Joyner, 2008; Hajek, Humphrey, & McRobbie, 2010; Lo, 2010; Miller & Crawford, 2010). Participation in online support groups (online forums or chat groups where individuals can share health and personal information) has also been linked to a sense of well-being and social support (Smedema & McKenzie, 2010). Online support groups provide interaction, shared knowledge, and support among individuals and contribute to a sense of empowerment for those with conditions such as eating disorders, weight loss, arthritis, breast cancer, and fibromyalgia (Hwang, Ottenbacher, Green, Cannon-Diehl, Richardson, Bernstam & Thomas, 2010; McCormack, 2010; van Uden-Kraan, Drossaert, Taal, Shaw, Seydel & van de Laar, 2008). Griffiths, Calear and Banfield (2009) reported that in an analysis of the studies on the effect of online support groups for people with depression, 62.5% of the studies showed positive results for participants in an online support group. In a study of 640 patients with HIV/AIDS, online support groups best supported participants who were female, young, single and the most ill out of all patients. In addition, the use of online support groups assisted participants in dealing with care, planning, disease-coping and informational support (Mo & Coulson, 2010). In a study of individuals using the online social support group hosted by *PatientsLikeMe,* up to 41% of the individuals dealing with chronic disease (e.g., HIV/AIDS), and 21% of those dealing with mental health concerns (e.g. mood disorders), indicated that they required less in-person care to manage their health when participating in an online community (Wicks, Massagli, Frost, Brownstein, Okun, Vaughan, Bradley & Heywood, 2010). Online support groups offer all the benefits of in-person support groups (e.g., kinship, understanding, a forum for discussion and learning, emotional support, etc.) while not being bound by time and space constraints associated with in-person group participation (Sullivan, 2008). The sense of anonymity provided through online communication may also be appealing to online group participants. Furthermore, with the rise of social networking sites, from MySpace© to Facebook©, informal online social support groups are increasingly forming for the purposes of cause activism, information sharing, fundraising, or caregiver support (Bender, Jimenez-Marroquin, & Jadad, 2011). In some cases, chronic diseases (e.g., pediatric diabetes) require that patients have access to the type of continuous support and care that an in-person clinic cannot provide (Nordfeldt, Hanberger & Bertero, 2010). Informal online support groups using Web 2.0 technology can positively contribute to the care challenges of high-needs clients (Nordfeldt, Hanberger & Bertero, 2010).

With the understanding that the 'client' is the entire family, the Parkinson Society suggests that the nature of PD necessitates social support as crucial to disease management and living strategies (Trepanier, 2007). It is not only the individuals with PD who make use of these support groups; rather, the Parkinson Society reports that support groups are equally important for Parkinson's caregivers, who face their own set of unique challenges and lifestyle changes (Dumoulin, 2007).

Lieberman (2007) investigated online resource use among individuals with PD and found that participation in social support groups was helpful in managing the considerable psychosocial effects of PD. Reportedly, between 40 to 60% of PD patients suffer from depression and lack of social support (Davie, 2008; Lieberman, 2007). Caregivers of individuals with PD are more prone to loneliness than any other caregiver group with the exception of caregivers of individuals diagnosed with Alzheimer's disease (McRae, Fazio, Hartsock, Kelley, Urbanski & Russell, 2009). However, participation in in-person support groups significantly increased perceived support and decreased loneliness for these caregivers (McRae, Fazio, Hartsock, Kelley, Urbanski & Russell, 2009).

Interestingly, of 66 participants in a professionally facilitated online Parkinson's support group, researchers found that participants were generally younger (average age: 60.2 years), were less depressed, and had a higher quality of life relative to in-person support group participants (Liebermann et al., 2006). In assessing the online readiness of individuals with PD, researchers found they were eager to participate in online support groups (Liebermann et al, 2006). When grouped into heterogeneous (both young and old onset with variable time since diagnosis) and homogenous (only young onset patients, or only newly diagnosed patients) online support groups, researchers found that participants in homogenous online groups showed the greatest improvements in emotional and physical well-being, but participants in both groups showed a decrease in depression and an increase in quality of life (Lieberman et al, 2006).

2.3 Electronic healthcare in Canada

The government of Canada has proposed a national e-health program for all Canadians (Canada Health Infoway, 2005; Pascal, 2001). This vision for Canadian health care includes the electronic health record (EHR) plus the use of online information sources (e.g., Veteran Affairs programs to teach veterans to find health information on the Internet), and other interactive health resources (e.g. PHRs, telehealth resources, national electronic disease surveillance systems, etc.), many of which permit individual input of personal health data (Pascal, 2001). Canada Health Infoway, a not-for-profit organization created and funded through the Canadian federal government, refers to e-Health as "a consumer-centred model of health care where stakeholders collaborate, utilizing ICTs [information and communication technology], including Internet technologies to manage health, arrange, deliver and account for care, and manage the health care system" (Alvarez, 2002, "Promise of e-Health," para.3).Health Canada defines e-Health as applying communication and information technology to healthcare in hospitals, home care, and primary care settings (Health Canada, 2010). The EHR is portrayed as fundamental to development within e-Health (Health Canada, 2010). E-Health is seen as a potential way to meet the diversity of Canadian health care needs, and has the possibility to be integrated through the full range of clinical health settings (Alvarez, 2002; Canada Health Infoway, 2005).

In a systematic review, eHealth as a term was tacitly understood as encompassing overlapping aspects of health and technology, and, to a lesser extent, commerce, activities, outcomes, places, perspectives and stakeholders that deal with health and technology (Oh, Rizo, Enkin, & Jadad, 2005). Electronic healthcare can encompass a wide range of services (e.g., telehealth, electronic prescriptions, electronic transmission of test results), tools (e.g., electronic health records), and resources (e.g. electronic registries, repositories for clinical data).

Individuals use the Internet for health purposes as diverse as information seeking for self or others, self health management, or for specifically designed health care interventions (e.g. smoking interventions) (Rainie & Fox, 2000; Riper, Andersson, Christensen, Cuijpers, Lange & Eysenbach, 2010; Wagner, Baker, Bundorf, & Singer, 2004). In fact, a recent issue of the Journal of Medical Internet Research was devoted to "e-mental health," a term used to describe the growing sector of Internet resources to deal with issues ranging from alcohol and tobacco addictions to depression and other mental disorders (Riper, Andersson, Christensen, Cuijpers, Lange, & Eysenbach, 2010).

Canada Health Infoway (CHI) is mandated to work with the provinces and territories to create a nation-wide system of electronic health records (Canada Health Infoway). From tele-health to public health surveillance and drug information systems, CHI programs are aimed at increasing the widespread dissemination and use of electronic health records across Canada. CHI envisions an EHR system that would allow health care teams to share patient information, diagnoses and advice across distances and among differing professions, as well as allow patients direct access to their health care records at any time. The Infoway report, *Vision 2015: Advancing Canada's Next Generation of Healthcare,* suggests that a network of electronic health records is increasingly necessary due to: (a) the continued increase in patient consumerism (and therefore patient need for up-to-date health information and choices), (b) the continued rise of chronic disease and age-related health issues in the Canadian population, (c) a shortage of doctors, therefore limiting access to primary care resources, (d) an increased need for community/home care co-ordination necessitated by the shift from acute to home-based health care settings, and (e) the demand for increased efficiencies and quality care (Canada Health Infoway, 2005). Current federal health minister Leona Aglukkaq strongly supports the CHI mandate and believes that the development of an electronic healthcare infrastructure will support economic growth, improve health care efficiency and save lives ("Government of Canada Supports Electronic Health Record System," 2009). CHI's 2010-2011 annual report states that 50.1% of Canadians now have access to the 'core elements' of an EHR system (Canada Health Infoway, 2011).

The development of electronic health care in Canada still faces challenges before it can become fully integrated into day-to-day health care. The CHI 2010-2011 report regards adoption and use of EHR systems as the new goal, rather than simple availability of EHR systems (CHI, 2011). Canada currently uses PIPEDA (Privacy Information Protection in Electronic Documents Act) as the federal legal framework to regulate the use and storage of health care data information (Wang, 2009). As a framework, PIPEDA provides guidelines in two sections about the privacy protections needed for both personal data (including health data) and electronic documents. The health privacy sections of PIPEDA were fully implemented on January 1, 2002, and are only superseded by provincial legislation on data privacy (Frazier, 2004; Schwartz, 2002; Wang, 2009). The effects and boundaries of PIPEDA, and its interactions with provincial legislation, will be further discussed in following sections of this literature review.

2.4 Electronic health records and personal health records

The following discussion of electronic health records (EHRs) and electronic personal health records (PHRs) is useful to contextualize the discussion of informal personal health records that follows. As mentioned previously, there are currently two broad categories of computer-based health records available at this time: electronic health records (EHRs) and electronic personal health records (PHRs). The question of who enters and controls the data in the records distinguishes these two different forms of computer-based health record systems. An electronic health record or electronic medical or patient record (EHR) is commonly controlled by the health care provider, which includes primary care physicians, specialists, hospitals, clinics, or health care organizations that offer health plans and medical care to their members (Sprague, 2006). Electronic personal health records (PHRs), however, are controlled by the patient/consumer, meaning that it is the consumer who determines information access, and the consumer who creates, maintains and undertakes data entry into the record (ISO, 2005). Operating in many of the same ways as an EHR, the PHR allows the health care consumer to enter their own information about drug regimens, appointments, symptoms and diagnoses, immunizations, lab tests, and so on. At the discretion of the health care consumer, specified health care professionals can be given permission to either view or download parts of the consumer's PHR (Kim & Johnson, 2002).

Possible uses for EHR systems include patient care documentation, electronic patient referrals, electronic billing, access to research literature, database development, automatic appointment reminders, and electronic scheduling (Boulus & Bjorn, 2008; Sidorov, 2006; ISO, 2005; Zimmerman, 2010). EHRs are generated by medical professionals' documentation resulting from instances of health care interaction, such as hospital or physician visits, etc. (Bleich & Slack, 2010; Sidorov, 2006). In the U.S., the capacity of EHRs to accumulate a comprehensive overview of a patient's clinical health history is translated into a potential health care costs saving of $77 billion dollars a year; EHR systems increase efficiency and co-ordination in patient care, show a positive return on investment into the system, improve communication between disparate health care professionals and decrease errors in prescriptions and medications (Cheriff, Kapur, Qiu & Cole, 2010; Milstein & Darling, 2010; Zimmerman, 2010). EHRs are also touted as being part of the solution to disaster-based health care delivery through instant availability of electronic access to patient health records (Benjamin, 2010). In Canada, Canada Health Infoway's goal was to have an operational EHR for 50% of the Canadian population by 2010; as this was not reached, however, the goal was reassessed and both CHI and eHealth Ontario aim to extend EHRs to 100% of Canadians by 2015 (Canada Health Infoway, 2005; Deutsch, Duftschmid & Dorda, 2010; Talaga, 2010). The adoption of EHR systems faces persistent challenges such as a lack of user-friendliness, over-complicated task requirements, fears that EHR adoption will decrease physician productivity, the expense of EHR initiatives and potential unreliability in electronic systems (Cheriff, Kapur, Qiu & Cole, 2010; Saitwal, Feng, Walji, Patel & Zhang, 2010).

An ongoing concern with EHRs is in regard to the distribution and security of information. Pyper, Amery, Watson and Crook (2004) found that patients in the UK reported issues of security and confidentiality, identity fraud and insurance company access to EHRs as concerns even with bio-metrically secured (e.g., accessible only with a patient's fingerprint, and/or eye-scan) systems. Consumers held differing opinions about who should be able to access their records; opinion varied from allowing any health care worker to access the records (majority of respondents) to restricting access to specifically named health care professional (Pyper, Amery, Watson & Crook, 2004). Due to the structure of EHRs, and the lack of consumer control over distribution of EHRs, potential exploitation of health care information by the government, the police, insurance companies, employers or the general public was cited as a wide-spread concern over system wide EHR implementation (Pyper, Amery, Watson & Crook, 2004). Despite these concerns, however, health care consumers reported that information was more accessible, changes to the record were both quicker and easier, and the electronic record allowed health care providers and patients to keep better track of tests, appointments, and diagnoses (Pyper, Amery, Watson & Crook, 2004).

Electronic personal health records (PHRs), for the purpose of this research, shall be defined as those electronic based records in which the health care consumer controls the data entry, viewing ability and transferability of the record. The consumer may allow health professionals to enter information (such as results from lab tests, etc.) directly to their PHRs, or allow their PHR to be accessed by health care professionals, but this happens only with the permission of the health care consumer (ISO, 2005; Sprague, 2008). Internet based PHRs (e.g., Microsoft Health Vault, Dossia) allow health care consumers to download medical records, add personal health information, and determine distribution of these personal health records to caregivers, medical professionals or hospitals (Eysenbach, 2008; McBride, 2008). PHRs such as those offered by Microsoft are often endorsed as 'empowering' devices, enabling the consumer to have ownership of their personal health data, and to increase healthcare efficiency through the prevention of duplication of care (e.g. assessments, tests, medication, etc.) (Kim & Johnson, 2002; McBride, 2008; Sprague, 2006).

An integrated system of PHRs and EHRs has been proposed (Sprague, 2008). This 'one patient-one record' model would provide a comprehensive record of client health and would contribute to the resolution of the flaws in the health information infrastructure that were exposed by Hurricane Katrina, the avian flu pandemic, and other such natural disasters (Endsley, Kibbe, Linares & Colorafi, 2006; Sprague, 2008; Tang, Ash, Bates, Overhage & Sands, 2006). For example, having a working system of PHRs and EHRs could prevent having to create things like the hastily-made *KatrinaHealth,* where electronic records had to be abruptly pulled together or formulated before health care could be administered to those injured in the disaster (Endsley, Kibbe, Linares & Colorafi, 2006; Tang, Ash, Bates, Overhage & Sands, 2006).

As health care expands and patients are expected to co-ordinate more elements of care (including multiple consultations, visits to different clinics, medication schedules, etc.), electronic health record and personal health record networks will be increasingly required to provide seamless care (Pratt, Unruh, Civan & Skeels, 2006; Tang, Ash, Bates, Overhage & Sands, 2006). Yet, consumer use of PHRs in Canada has been even lower than provider uptake of EHRs; PHRs are individual-centred rather than clinic or hospital-centred and PHR adoption is not necessarily as heavily promoted by health care professionals (Tang, Ash, Bates, Overhage & Sands, 2006). Nevertheless, experts argue that the integration of PHRs and EHRs into a cohesive network is the ultimate goal (Tang, Ash, Bates, Overhage & Sands, 2006).

2.5 Informal Personal Electronic Health Records

Although a great deal of inquiry has been focused on personal health care records, ranging from the legal and ethical problems to the economic costs and benefits (Carter, 2000; Gostin, 1997; Hillestad, Bigelow, Bower, Girosi, Meili, Scoville, & Taylor, 2005), recognition and awareness of informally created personal health records is still developing. Beyond the patient/consumer data captured in EHRs and PHRs, personal health information is also scattered throughout the Internet in the form of e-mails, appointment bookings, prescriptions, search records, support groups and other web resources (Wang 2009). As Dyson (2008) points out, consumers today are constantly faced with new, and never before seen reasons, especially in the social and healthcare fields, to post personal information online. At the same time, it is becoming increasingly difficult to maintain an anonymous presence online. Consequently, 'informal' online health care records are unintentionally being established through an aggregation of consumers' existing online personal health information. Health care consumer's personal health information may increasingly become accessible to the public in ways that formal electronic health records guard against. In a survey of over 14,000 individuals from seven European countries (e.g. Denmark, Germany, Greece, Latvia, Norway, Poland and Portugal) researchers investigated consumer online health information seeking behaviours, and found that 22.7% of survey respondents were using the Internet for interactive health care, rather than simple health information retrieval (Kummervold et al, 2008). Approximately 10% of survey respondents were actively contributing their personal health information as part of an electronic support group, and although these individuals were not aiming to create an electronic health record, they contributed much of the information typical of an EHR (Kummervold et al, 2008). In the era of Health 2.0, the trend towards increased use of resources such as blogs and chat groups is creating a situation in which personal health information is becoming widely and openly distributed (Adams, 2010; Dyson, 2008). An investigation of patient medication use found1,948 treatment histories posted on the health based social networking site *PatientsLikeMe©* by network participants (Frost, Okun, Vaughan, Heywood & Wicks, 2011). These treatment histories included information about when the individual started taking the drug and their purpose for doing so, as well as side-effects they experienced, the efficacy of their treatment, and their evaluation of the drug on a whole (Frost, Okun, Vaughan, Heywood & Wicks, 2011).

The phenomenon of informal records is perhaps best illustrated through the process of obtaining consent for research participation. King (1996) noted that virtual communities on the Internet allowed researchers to access unprecedented amounts of personal information and interpersonal communication without consent from the individuals who had posted it. Willison (2003) comments similarly on Canadian Internet policy, noting that PIPEDA allows for researchers to make use of publicly available personal information, a phenomenon known as making “secondary use” of personal health information (Willison, 2003). The amount of research based on online personal information points to the growing prevalence of informal records of health information. In 2004, Yahoo!Groups (an online group development site hosted by Yahoo) contained approximately 25,000 groups under the health and wellness category and “thousands” of Internet-based support and chat groups, all of which are informal repositories of personal information that are available to the public (Eysenbach, Powell, Englesakis, Rizo & Stern, 2004).

More and more, consumers are comfortable in posting their personal information within online health care sites (Sullivan, 2008). Frost and Massagli (2008) found that patients accessed and browsed through other patient’s personal health information using services like PatientsLikeMe©, to create relationships that allowed for social support and information sharing. The creation of informal health records through postings of personal information to online support group discussions and communities constitute an important contribution to the development of meaningful and useful online support groups (Frost & Massagli, 2008; McCormack, 2010; Moak & Agrawal, 2010). The Internet has been described as “the most comprehensive electronic archive of written material” and both physicians and researchers are frequently confounded by the amount of personal health information available online (Eysenbach & Till, 2001).

2.6 Canadian laws and policy, and electronic health privacy

In Canada online information privacy policy has been increasingly shaped by the widespread adoption and use of Internet social networks and communities such as Facebook©, Tumblr©, MySpace©, and Twitter©. Dwyer, Hiltz and Passerini (2007) found that the development of new online relationships through social networking sites such as Facebook© and MySpace© did not require the same 'building of trust' between individuals as in-person social connections required. Furthermore, although privacy was a concern, individuals were still building online relationships with strangers through sites (e.g. Facebook©, MySpace©) where privacy protection can be weak (e.g., the sites record all social interaction and personal information can be accessed through friends' social connection networks) (Dwyer, Hiltz, & Passerini, 2007; Fogel & Nehmad, 2009). Interestingly, individuals' privacy concerns related to social network participation were linked to either their trust in the social network (e.g. Facebook©, match.com©, Friendster©, LinkedIn©) to protect their privacy, or participants' misconceptions about the enormity of the size and accessibility of the social network (Aquisti & Gross 2006; Dwyer, Hiltz, & Passerini, 2007; Fogel & Nehmad, 2009). Acquisti and Gross (2006) found that with social networks such as Facebook©, the strength of participant information privacy concerns was not correlated with the amount of personal data that they released on their network profile. The willingness of individuals to disclose personal information to online social networks who, in accordance with their business plan *want* this personal information to be available to other businesses and consumers, is changing the conventional conception of information privacy protection (Acquisti & Gross, 2006). The growing trend towards the creation of online public profiles (whether purposeful or not) represents a significant change in the way individuals manage their personal information. This change in the perception of online privacy, trust and relationships may have widespread consequences for the way we perceive, guard, and legislate information privacy.

In the Vanderbilt Law Review on *Protecting Health Information Privacy* (Glenn, 2000), the author suggests that privacy was so important to health care consumers that 1 in 6 American adults had done "something unusual" to maintain their information privacy. These behaviours included actions such as paying cash for medical services rather than allowing documentation of their personal data by the health care provider. Reportedly, patients have even stopped treatment when it appeared that their privacy might be breached (Glenn, 2000).

In the Canadian context, Willison (2003) suggests that while Canada and Canada Health Infoway have created an "ambitious plan" for integrating healthcare and the Internet, concerns regarding privacy and health information remain outstanding. According to CHI, these concerns include a wide range of accountability, regulation, rights, and technical issues including jurisdictional issues in governance of private information, finding methods to limit collection and disclosure of personal information, clarifying the chain of information custodianship, etc. (Canada Health Infoway, 2007). Citing national health reports including the 'Romanow report' (Romanow, 2002), Willison suggests that the challenge currently facing Canadians is the ability to balance the need for personal privacy and protection of sensitive data against the equally pressing need of allowing access by health professionals and other individuals who would make best use of the data. Currently, the spread, collection and use of personal data is regulated both at the federal and provincial levels through acts such as PIPEDA and PHIPA (Ontario's health privacy legislation), both of which are discussed below (Willison, 2003).

General data privacy in Canada is regulated by the federal Personal Information Protection and Electronic Documents Act, or PIPEDA. Created April 13, 2000 and fully implemented as of January 1, 2004, PIPEDA is "an Act to support and promote electronic commerce by protecting personal information that is collected, used or disclosed in certain circumstance, by providing for the use of electronic means to communicate or record information..." (Berzins, 2004; Frazier, 2004; PIPEDA, 2000; Schwartz, 2002). PIPEDA requires health, commercial or other organizations to allow individuals access to any of their personal information that the organization has collected. This right is only waived in certain circumstances, such as when allowing an individual access to their own data would also inadvertently allow access to a third party's personal information (PIPEDA, 2000). PIPEDA also sets out guidelines for the length of time an organization is allowed to hold on to personal information, and the restrictions on data release (2000). PIPEDA enforces regulations ensuring that organizations gain consent from any individual from whom they gather personal information and that the information is collected in a fair and confidential manner and PIPEDA applies to all private, commercial organizations. For the purposes of PIPEDA, an 'organization' can be anything from an individual to a partnership or association that deals with personal information in the course of commercial activity (PIPEDA, 2000). Besides PIPEDA, provincial regulations, such as Ontario's Personal Health Information Protection Act (PHIPA), regulate data protection in the provinces and territories; in Ontario, PHIPA outlines the requirements for consent in collecting, storing, or handling personal health information and electronic health records, as well as controlling the access and disclosure of personal information (PHIPA, 2004). Within Ontario, the rules of PHIPA supersede those of PIPEDA, as PHIPA has regulations in data protection equal to or greater than those of PIPEDA.

How does this relate to health information? For the average health care consumer living in Ontario, their private health data and the organizations who gather it will be subject to: (1) PIPEDA, (2) the federal Privacy Act of 1985, which was the precursor to the development of PIPEDA and (3) their provincial privacy regulations. It should be noted that Freedom of Information and Protection of Privacy Act (FIPPA) would affect personal health information being kept by government institutions such as hospitals, but is therefore outside of the scope of this review. The oldest of the regulations, the Privacy Act differs from PIPEDA in that in guarantees the right of the individual to gain access to any of their personal information that might be stored in an information bank or within a government institution, rather than from commercial organizations. Within the Privacy Act personal health information is not defined separately, but is rather incorporated in all regulations dealing with 'personal information.' The Privacy Act, due to its enactment date, does neglect to deal specifically with Internet-related privacy issues. (Please note that a chart of the different legislation referred to here can be found in Appendix F.)

PIPEDA (Personal Information Protection and Electronic Documents Act) is the current federal legislation on the use, disclosure, gathering and protection of personal information and the most germane in the realm of health data privacy protection (PIPEDA, 2000). For PIPEDA, this includes any information involving: (a) an individual's mental or physical health; (b) the health services accessed by a given individual, or any information gathered during an individual's use of health services; (c) information gathered about or during any biological donations that an individual may make (including body parts, blood, etc.) and (d) data that is 'collected incidentally' to an individual's use or access of health services (PIPEDA, 2000). PIPEDA is most relevant given the global nature of the Internet; provincial regulations apply to hospitals, clinics and organizations within the province's borders, but any information that spans these borders also comes under the regulation of PIPEDA (PIPEDA, 2000). PIPEDA, however, allows for the free collection, use or disclosure of personal information if the information is publicly available (PIPEDA, 2000). Under PIPEDA, information that is posted to an open, online community could be considered 'publicly available,' and open for the use, collection, or disclosure by any interested parties, whether they be governmental, research, or for-profit. The issue of 'publicly available' information remains contentious and has yet to be fully clarified.

Although PIPEDA might be the most influential Canadian legislation on information privacy, citizens of Ontario are regulated also under PHIPA. Rather than regulating organized electronic/paper health *records*, PHIPA regulates the dispersal of personal health information in any form and any size and this includes personal health information posted within the online environment (e.g. to online support groups). This distinction is important in that PHIPA theoretically provides the same amount of regulation and protection for informal records as it does formal electronic health records. PHIPA also introduces the idea of a health information custodian. A health information custodian, under PHIPA, is defined as any individual or organization that controls or possesses another individual's personal health information. According to PHIPA, this includes health care professionals, the operators of pharmacies, nursing homes, hospitals, clinics, ambulances, or other health care services, government ministry workers, and anyone else who in the course of their professional duties comes into contact with recorded personal health information (with the exclusion of certain groups, such as Aboriginal midwives). PHIPA holds each health information custodian personally responsible for ensuring that information they hold is accurate, up-to-date, and well protected from unauthorized use, collection or transmission (PHIPA, 2004).

For health care consumers that make use of online support groups, any information that they post comes under the jurisdiction of PIPEDA. However, with the Internet being a global phenomenon, issues of which country (and thus, which respective set of laws) has jurisdiction is complicated. The Privacy Commissioner of Canada indicated that any organization that "has an operating presence inside Canada, and collecting the personal information of Canadians... is subject to Canadian law" (Office of the Privacy Commissioner of Canada, 2010). However, enforcing Canadian law on non-Canadian organizations or halting the flow of information out of Canada can be difficult (Frazier, 2004; Office of the Privacy Commissioner of Canada, 2010). In the United States, data protection legislation does not apply to data that has been anonymised by the individual who collected the data from the Internet. Health information, for example, posted on online support groups hosted in the U.S. is regulated by American regulations; U.S. regulation could therefore affect those in Canada using American-based support groups (Kalra, Gertz, Singleton, & Inskip, 2006). As both PIPEDA and American privacy legislation are in-line with the regulations set up by the European Union, free-flowing data transfer of anonymised data is also possible between the U.S., Canada, and the member countries of the E.U. (Frazier, 2004; Lawlor & Stone, 2001; Nisker, 2006). As these developments were originally undertaken to facilitate electronic commerce, the full implications for personal health information are not completely understood, and there has been little research on Canadian privacy laws pertaining to health information, within a global context (Frazier, 2004; Racicot, 2005). How Canadian data privacy laws interact with international laws is therefore potentially of interest in meeting the needs of Canadian health care consumers.

The Privacy Commissioner has indicated the need to create and enforce regulations for non-compliance with PIPEDA, and is considering a public disclosure of the names or organizations that are non-compliant with PIPEDA standards (full disclosure is currently not allowed); these changes may alter the way that organizations, both health-based and otherwise, compile and keep personal information (Geist, 2011).

2.7- User's perspectives on the Internet and online health

Recent studies suggest that a majority of individuals who use the Internet for health related reasons expressed concern over privacy while using online health care resources (Im, Chee, Lim, Liu, Guevara, & Kim, 2007; Ngeno, Zavarsky, Lindskog, & Ruhl, 2010). Brann and Anderson (2002) identified that individual's uncertainty about the accuracy of information, fear of privacy violations, and concern about conflicting interests between advertisers and website owners, were the major barriers to comprehensive use of online health resources (Anderson, 2004; Brann & Anderson, 2002; Fox & Rainie, 2000).

An interesting paradox has developed related to consumer perception and use of online resources, whereby consumers' self-reported concerns about the disclosure of their personal information over the Internet contrasts with behaviour that contradicts, or is in opposition to their privacy concerns (Carroll, Zimmerman, Rivara, Ebel, & Christakis, 2005; Norberg & Horne, 2007). Although individuals cited issues of information privacy as personally concerning, researchers found that individuals regularly disclosed more information than they originally indicated they would be comfortable disclosing (Norberg & Horne, 2007).

Users of online networks and websites show an optimism bias or a selective bias which leads them to underestimate the risk to self due to privacy breaches or excessive disclosure (Cho, Lee, & Chung, 2010). This contradiction between belief and behaviour may also reflect the tendency of online participants to underestimate the size and scope of the online network, along with an underestimation of the risks associated with online disclosure behaviours (Acquisti & Gross, 2006; Ngeno, Zavarsky, Lindskog, & Ruhl, 2010). In trying to understand this contradiction between privacy attitudes/beliefs and behavioural conduct, researchers also suggest that the desire for instant gratification, and the inability of the consumer to predict long-term consequences of their 'disclosure behaviour' as plausible, and that only a true appreciation of the long-term consequences of releasing personal information will change disclosure behaviours (Norberg & Horne, 2007).

Studies on consumer perception of online information privacy indicate that the current policies are not sufficient protection for the consumer. Goldman, Hudson, and Smith concluded that the privacy policies of 21 large online healthcare websites were inadequate in terms of consumer protection (2000). Online ranking systems, indicating the quality of information and degree of information privacy, or self-regulation of information quality and privacy by health care websites, have proven ineffective in protecting the privacy of health care consumers (Brann & Anderson, 2002; Culnan, 2000). Consumer comprehension of website information privacy policy is further compounded by the need for advanced literacy skills necessary to read most website policies. In fact, the average health care website requires the consumer to have a college level literacy skill to understand the websites' privacy policies (Goldman, Hudson, & Smith, 2000; Graber, D'Alessandro, & Johnson-West, 2002). Similarly, studies on the privacy policies of pharmaceutical-sponsored websites indicate that readability and compliance with security regulations are low (Sheehan, 2005). As these are American studies, whether the current situation in Canada is the same, considering the developments that have taken place in privacy legislation, seems to be an area requiring more research; for users of online healthcare resources, however, their perceptions and concerns about privacy may be a barrier to use, and lack of protections to deal with those concerns may compound the barrier to use.

Why this is an important issue

With Parkinson's disease affecting a growing number of Canadians, Health 2.0 resources (e.g., interactive online support groups) are becoming key healthcare strategies. As health information technology advances, it is important to recognize elements that may help or inhibit the type and quality of online consumer health care. For individuals with PD, limited mobility, limited social contact, and the degenerative and chronic nature of the disease means that these individuals require information, coping methods, and support that varies with the progression of their disease. With an increase in Internet use among seniors, individuals with PD seem to be a group who might appreciate the convenience and ease of access to Internet resources. Perceptions of privacy, however, can restrict, change, limit, or otherwise influence the use of online health resources. Currently, gaps exist in the literature in addressing privacy and informal electronic health record development among individuals with PD, and, more importantly, how perceptions of privacy in individuals with PD shape their use of Health 2.0 resources. This research therefore aims to address how older Canadians with chronic disease (PD) understand their privacy with regards to accessing and sharing health information online.

CHAPTER 3: METHODS

3.1 - Research Question

What are the opinions, perceived issues, and concerns of individuals diagnosed with Parkinson's Disease, with regards to information privacy and confidentiality on the Internet, and specifically in using Internet based PD resources?

3.2 - Research Rationale and Paradigmatic Background

This study is a qualitative descriptive study that focused on the perceptions that individuals with Parkinson's disease have about personal information privacy and confidentiality on the Internet, and, more specifically, on Internet-based Parkinson's resources. Qualitative description was chosen so that these results may provide a straightforward and comprehensive exploration of the topic, in the participants' own words (Sandelowski, 2000). As described by Milne and Oberle, "qualitative research seeks not to reveal 'truth' but to generate insights" into the perspectives and perceptions that the research participants in the study hold (2005, p. 414). This qualitative descriptive research approach allows the formation of a basic understanding of the phenomena under investigation (Sandelowski, 2000). The interpretation seeks to highlight important ideas arising from the data, while neither ascribing meaning from 'reading between the lines,' nor applying an outside theoretical perspective or lens, instead striving to remain true to the voice of the participants (Sandelowski, 2010). The qualitative descriptive methods used in this study are based in the theoretical framework of *naturalism,* which requires analysis to be kept unabstracted and as close to the original data as possible (Sandelowski, 2000; Sandelowski, 2010).

Qualitative descriptive research, applied to this project, will generate a starting point to understanding the basic issues and concerns surrounding information privacy for individuals with PD. In turn, this understanding will allow for the development of both programs that better addresses the needs and perceptions that individuals with PD hold, and Internet-based resources that will address these worries and concerns. As little research exists at this time on the perceptions of privacy held by individuals with PD, qualitative description, with its focus on comprehensive, descriptive results, is best suited to beginning to address the challenges that will need to be taken into consideration if effective and comprehensive Internet-based PD resources are to be developed.

3.3- Ethics approval and recruitment notice

Originally, this study was planned as a mixed methods study with individuals recruited online. Ethics approval was obtained for this. Due to difficulties in recruitment, ethics was amended and re-obtained to allow for the change to in-person recruitment, with the methods of doing so outlined below. The recruitment notices were also vetted at this time; each recruitment notice contained a brief outline of the research with a request that any interested parties contact the researcher via e-mail or telephone. The contact information for the researcher was highlighted for ease of access. The recruitment notice can be seen in Appendix B.

3.3 – Participant Recruitment

Convenience sampling was used for the purposes of recruitment (Marshall, 1996). Initially, online recruitment was done through several online Parkinson's communities/forums/groups who were identified through Google-searching using the combined search terms of 'Parkinson's, Canada, online groups.' In each case, an e-mail was sent to the moderator or contact person for the online support group or forum seeking permission to post a recruitment notice to the site. This e-mail outlined the basic purpose of the research and how the recruitment process would proceed. With permission, notices were posted to the following groups: two Facebook© groups, the Parkinson's disease section of the HealingWell© forum, the Parkinson's disease section of the eHealth forum, and in the myParkinsons.org© community. According to statistics available for one forum, over 300 individuals clicked on and read the recruitment notice; each Facebook© group also had over a 100 members but membership and/or traffic statistics were not available for the other groups. However, no responses were received to any of these online recruitment notices, and therefore online recruitment was halted and the recruitment protocol was adjusted with research ethics board approval for offline and in-person recruitment. It should be noted that recruitment online addressed the original mixed-methods project, namely both a survey and an interview.

Offline, in-person participant recruitment was conducted through local Parkinson's disease groups, resources, or communities. These included the Parkinson's support and exercise groups of the Parkinson Society Southwestern Ontario, the Parkinson's support and exercise groups of the Parkinson Society Central and Northern Ontario, the Parkinson's exercise groups at Parkwood Hospital, and the Movement Disorders clinic at University Hospital, London Health Sciences Centre. Together, these larger groups oversaw approximately 21 individual Parkinson's groups within the area of Ontario from Toronto, east to Chatham-Kent, including those in Markham, Vaughan, London, Windsor, Grey and Bruce counties, Guelph, Kitchener-Waterloo, etc. All groups were initially located through a basic search in Google using the terms 'Parkinson's disease, London, Ontario, groups'. In each case, a facilitator or organizer for each group was approached with a request to speak to the group participants about the research project and the opportunity for members of the group to participate. This presentation was five minutes long, with additional time for questions and discussion, with interested individuals invited to contact the researcher should they be interested in participating. Paper copies of the recruitment notice were also distributed to the individuals present in each group. Permission was granted, and presentations made, in the Strathroy-Caradoc, Brantford, Stratford, London, Kitchener-Waterloo, and Chatham-Kent support groups, as well as in four exercise groups at Parkwood Hospital in London totalling approximately100-150 individuals. The request to speak about the research was declined by several groups and instead the participant recruitment notice was provided to each PD group facilitator with the request to disseminate the notice to the group members. Similarly, the Movement Disorders Clinic of the London University hospital allowed the recruitment notice to be posted in the waiting room of the hospital clinic. Snowball sampling, a form of convenience sampling where participants are asked to recommend other individuals who might be interested in participating, was employed in this case, with each participant being asked to pass along the recruitment notice to others that they knew to be eligible to participate (Kuper, Lingard, & Levinson, 2008). Numbers were not available for how many individuals would potentially have observed the notices in the Movement Disorders clinic.

In-person recruitment for this study was based on the original goal of a two-part mixed methods study, composed of a quantitative survey section and a qualitative interview section. In the course of in-person recruitment, the study was narrowed to and data collection focused on the qualitative interviews only.

Basic descriptive qualitative research typically involves semi- to minimally-structured interviews that extend until the research reaches theoretical saturation, suggesting that the information gathered has answered the full scope of the question; reaching theoretical saturation is typically exemplified by the lack of new themes within the analysis process, and the continual re-appearance of themes that were generated by earlier interviews (Milne & Oberle, 2005; Sandelowski, 2000). Data gathering and analysis occurred concurrently through the course of this study. Participant recruitment was guided by the goal of theoretical saturation and availability of participants, and, as such, recruitment was ended after 10 viable interviews, when little new information was found and codes emerged repetitively (Milne & Oberle, 2005).

3.4 – Inclusion/exclusion criteria for participation

Participants were invited to volunteer for research participation if they were:(1) diagnosed with Parkinson's disease, and (2) had used the Internet at least once since they had been diagnosed with PD. This was expanded from the initial requirements; initially, participants were required to have made use of online PD groups or forums. Due to unforeseen recruitment challenges with the original inclusion / exclusion criteria, participants for this study were instead required to have PD and have made use of the internet since their diagnosis. Participants were excluded from this research if they had already explored and made use of (e.g., contributed material to, or frequently visited and gained knowledge from) an online Parkinson's disease support group or community. The exclusion criteria were purposefully left quite broad in order to facilitate a range of opinions and information from potential participants, as qualitative description demands (Sandelowski 2000; Sandelowski, 2010).

3.6 – Interview guide

The interview guide (see Appendix A) for this research was designed to facilitate understanding of the perceptions that individual's with Parkinson's disease hold about online information privacy and Internet-based Parkinson's support communities. The initial questions were designed to be factual, easy-to-answer questions, which allowed both participant and researcher to ease into the routine of the interview. The interview guide was created as a semi-structured document, and was edited, changed, and added to after each interview (Pope, Ziebland, & Mays, 2000). Supplementary questions were frequently guided by statements the participants made, from which the researcher would seek elaboration or greater detail. This strategy allowed the participant to discuss elements they thought were important with regards to the topic, and the researcher to probe for explanations or clarification (Milne & Oberle, 2005).

3.8 – Interview Participation

Volunteer participants contacted the researcher to set a date and time for the interview. All interviews were conducted over by telephone. Interviews ranged in length from 40 minutes to one hour. At the agreed-upon time, and in a private location, the researcher phoned the participant, checking at the beginning of the interview that the participant was still in good health and prepared to participate in the research. Before beginning the actual interview, the researcher asked permission to turn on the audio recorder, which was then left on for the duration of the interview. The letter of information describing the research project was reviewed with the participant, and any questions were addressed; participants were then asked to provide verbal consent to participate in the interview. They were also reminded at this time that they could stop the interview at any time, and had no obligation to answer any given question. Participants were also offered physical copies of the letter of information, should they desire it for their records.

At the end of the interview, participants were asked if they had any questions or knew of any others who were interested in the research and were also reminded that if they wished to know the outcomes of the research, that they could use the contact information on the Letter of Information to request a summary of the study findings.

3.9 – Data analysis

Transcription of the interview occurred directly after the interview, and was transcribed verbatim by the researcher, directly from the audio recording. This process occurred at a rate of approximately 4 hours of transcription for every hour of recording. In total, 14 interviews were conducted for this study. Although all participants were introduced to and thought to meet the inclusion criteria, following their interviews four participants were excluded for the following reasons:

1. One interviewee was a caregiver who did not, herself, have Parkinson's;
2. Two interviewees had previously made extensive use of Internet-based Parkinson's support groups and communities; and
3. One interviewee had never made use of the Internet.

Although initial plans were to include those who had previously made use of Internet-based PD support groups as a separate group in this research, the lack of participants – the two listed above were the only two found over the entire course of recruitment, which encompassed recruiting from several hundred people – made the analysis of these individuals as a separate group to be non valid for this research. During transcription, all identifying elements were removed from the transcription (such as names, locations, etc.) and the phone number of the participant was deleted from the researcher's list. Any relevant information regarding the context of the interview such as significant pauses, laughter, etc. were also noted at this time. Each interview was checked a second time, while listening to the audio recording, to check for transcription accuracy (Milne & Oberle, 2005).

Analysis of the interview data began with transcription. This allowed coding to begin as soon as the interview concluded; it also permitted the researcher to re-formulate or adjust questions as needed in-between participant interviews. Data collection and data analysis therefore overlapped, which allowed the researcher to refine lines of questioning and fill in gaps in knowledge as the interviews progressed (Pope, Ziebland, & Mays, 2000). The process of coding and analysis for this study, as espoused by the qualitative descriptive methodology, was used as a process to unearth and summarize themes and ideas that emerge from the data (Sandelowski, 2000). In service to this goal, codes were not pre-formed but were rather generated inductively from iterative readings of the data (Coffey and Atkinson, 1996; Sandelowski, 2000). Codes were generated from the participants own words, and were refined from interview to interview, as more appropriate or fitting codes emerged in subsequent interviews. As codes accumulated, themes emerged from the coding; similarly to the codes, these themes were reformed and adjusted as more interview data was accumulated.

Member checking was not conducted in the course of this study; with naturalistic qualitative research, it is acknowledged that participants revise their own stories as their own experience, current emotional states, and histories change (Sandelowski, 1993). Member checking therefore goes against the revisionist nature of the stories that participants are telling, subjugating the story told at the time of the interview in favour of a participant's current reality

(Sandelowski, 1993). Furthermore, in showing participants the final analysis, participants may not recognize their own experiences in the aggregated re-representation of a researcher's analysis, or be unable to recognize how the experiences of other participants reflect their own stories (Sandelowski, 1993). Attempts at member checking may also cause conflict between the goals of the researcher (to answer a research question, investigate the data) and the potential goals of the participant (reasons for why they may be participating in research), as well as causing conflict if the participant incorrectly remembers what occurred during the interview (Sandelowski, 1993). Member checking to corroborate what was said during interviews therefore does not fit with the paradigm of this research. Instead, to maintain rigour and validity in the research, coding and analysis were performed independently by two members of the research team, namely the lead researcher and the research supervisor. The results were then compared and discussed. The naturalism paradigm views reality to be constructed and therefore without a core, single truth, rigour is important, but assuring that the findings are repeatable is not a concern (Sandelowski, 1993).

During the course of the research, the researcher's pre-conceived notions concerning privacy and Internet use were checked through regular meetings with independent researchers (the advisory committee and supervising researcher) as well as discussion with the facilitators of the support groups and the Parkinson Society Southwestern Ontario (Koch, 2006). Rigour can be established through credibility and dependability of the research; in order to assist in establishing these elements, an audit trail was created through the notes taken from meetings with Parkinson Society facilitators and senior researchers, with the goal of personal reflexivity on the biases and the decisions made by the researcher (Koch, 2006). Notes were also taken during interviews; a basic interview guide was created, and then after each interview questions were modified or added to according to the notes taken during the interview (Koch, 2006).

After coding, data was re-represented by collapsing them into the major themes that emerged from the interviews (Sandelowski, 2000). This was not intended to re-interpret data, but to provide a structure through which they could be easily understood, and draw together important themes and aspects of the data (Sandelowski, 2000).

CHAPTER 4: RESULTS

Ten interviews were used for this study. The participant's profiles are shown in Table 1.

Table 1

Profiles of participants in this research

Total participants		**10**
Gender	*Male*	6
	Female	4
Age	*Mean*	71.4
	Median	73
	Range	Ages 58 – 84
Access to computer and Internet:	*In their home*	8
	Outside of home	2
Participates in an in-person PD support group?	*Yes*	8
	No	2
Recruited from	*Support groups*	7
	Other PD group	1
	Other	2
Years since PD diagnosis*	*Mean*	5.3 years
	Median	5 years
	Range	0.5- 10 years

*Note: This information was only provided by 8 out of the 10 participants.

Several themes and associated subthemes emerged from the analysis of the data; these include:

(1) Information privacy, including (i) defining private information, (ii) PD privacy exceptions, and (iii) online anonymity;

(2) Sources of knowledge about online information safety, namely from (i) media reports, and (ii) family and friends;

(3) Reasons for privacy concerns: (i) physical vulnerability, (ii) the lack of 'people' on the Internet, and (iii) attitudes toward privacy and disclosure; and,

(4) Non privacy related reasons for limiting the use of Internet resources.

These results are discussed below.

4.1. Information Privacy

Trust that their personal information would be kept confidential was often mentioned by participants as one aspect of privacy, and was linked to their likelihood of participation with online websites, communities, or services. When asked to describe information they considered private, participants spoke of financial, family, and health information.

4.1.1 Defining private information

All participants agreed that financial information was private and not to be shared. This was for two reasons: first, participants felt that the '*size of their bank account*' was their own business, and, secondly, worries were expressed about having financial information used for "nefarious" purposes and their savings stolen. Their caution concerning financial victimization was often linked to stories about online tricks and scams, which formed, in part, the source of participants' knowledge concerning Internet dangers. This sentiment was voiced by a participant who stated that, "*I wouldn't do my banking over the Internet.....* [because] *I guess I think* *somebody might get in and steal my money or something*" (Participant 14)[1]. Although not all of the participants could provide specifics, they would recall hearing stories of how elderly people were preyed upon and conned out of their life savings. When asked to explain further, one participant mentioned that

> *I just - I feel that sometimes... I feel that a computer wouldn't be safe when it comes to money, like you know when you see the viruses attacking the computers and stuff like that... like I wouldn't care if my name came up with Parkinson's or anything like that, but when it comes to finances I wouldn't want them to take the little bit I got - I've got enough to last me a lifetime that's it.* (Participant 14).

Private family information included identifying details about participants' children and spouses as well as family relationships and interactions (divorces, family problems, etc.). The acknowledgement that informal caregivers, who were often spouses, were negatively impacted by their spouses' PD was mentioned, and details surrounding the impact on the mental and physical health of caregivers, friends, and/or family were seen as private. This included the stress and strain caregivers felt, as well as the day-to-day details of how PD changed the routines of the entire family. As one participant mentioned,

> *As to how it* [PD] *affects the caregiver, and how you react to that.... you talk about a caregiver being a husband or a wife.... that has a huge impact, and that's, uh, private as to how you deal with that...* (Participant 11).

Also linked to protecting family information, two participants indicated that information about their sex life was information that should be completely private. According to the participants,

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[1] Participants were numbered chronologically for all fourteen interviews; although only ten interviews were viable for this research, the sequential numbering through time means that participants were numbered 1-14, which is maintained here.

this category of information is a "*private matter*" (Participant 3) that they would not feel comfortable discussing.

Health information was less clearly delineated as being 'private' or 'not-private' information than the previously mentioned categories. Participants indicated that some aspects of their general health information, for example, that they had PD were often *not* considered to be private, although information about their own and their family's emotional reactions to their PD was for some participants, seen as private information (the emotional reactions participants tended to speak of included frustration, depression, or hardship in dealing with their PD). Within the scope of health information, where the participant drew the line between private and public greatly varied. When asked to identify what types of health information would be kept personal, one participant mentioned:

> *...the medications and stuff like that that you're using... Like some people try to um... ah, self medicate.... with medications that they aren't supposed to have. ... And if... and if I were ever to do that, I wouldn't want that... blasted around the world.* (Participant 1).

Private information included information about medications or physicians (such as the participant above). One participant felt comfortable sharing anything concerning PD: *"I'm not very private about my Parkinson's disease,"* (Participant 11), while another wouldn't share any of their health information: "*I could be sitting in the group, and I could be thinking a lot but I wouldn't necessarily verbalize it* [health information]*"* (Participant 6). In general, the only thing agreed upon was that what one felt was 'private' health information depended on the circumstances, and that this privacy could be voluntarily breached in order to assist others with PD (discussed in section 4.1.2 below). One participant also mentioned denial of her PD as the reason for maintaining complete health information privacy and as the root cause of her unwillingness to share her health information.

When asked about their fears surrounding health information and privacy, participants spoke of fears that their personal health information could be accessed by unknown *"crooks,"* *"kooks,"* and other unidentifiable, Internet-based scammers and hackers.

4.1.2 PD Privacy Exceptions

When asked whether they would ever consider sharing their personal health information, participants identified an opportunity to help a fellow PD sufferer as a valid reason for disclosure of information about their PD. This ability to help would manifest itself in two ways. First, participants suggested they could help by giving their personal health information for research. There would be a willingness to disclose information that they normally otherwise would not in order to support PD research. Secondly, if someone on the Internet was in need of help or knowledge that the participant possessed, then participants felt compelled by empathy and ethics to share it, regardless of whether it was something they would not normally disclose. For example, one participant mentioned that she was unlikely to share any information at all online about her PD, but also said that she would share her personal information

> *if I thought it was going to... if I thought it was going to help somebody else, you know, it wouldn't be, it wouldn't be just because, you know, I want to tell everybody, go on the rooftops and tell everybody – but if I thought it was going to help somebody else, that's when I think it would be okay, to talk about it, and be involved in discussions, and so on and so forth...* (Participant 6).

This is not to say that there were no boundaries to what information would be disclosed under these circumstances – however, there was more flexibility in those boundaries should the disclosure be in service of providing help to another.

4.1.3 Online Anonymity

Participants identified anonymity as an important element of privacy on the Internet. This was generally expressed two ways: participants either suggested that they would be willing to provide information as long as it could not be traced back to them and their location (i.e., through their ISP, to their specific computer), or they were worried that information provided could be linked with personal identifiers such as their name. This was a concern specific to Internet use. Of those participants who worried about their anonymity, willingness was indicated to provide personal information (e.g., their name) to strangers at PD-based in-person support groups, but it was suggested that these participants would be unlikely to disclose this type of information within an online setting.

The reasons given for the importance of online anonymity differed. One participant stated that personal anonymity would allow him the freedom to candidly discuss his thoughts about his health care providers (e.g., neurologist), and issues with his treatment with others who have PD. When asked why those particular concerns would be easier to raise on the Internet, he mentioned the *"feeling that I'm never going to meet these people… and… that anything I say is much less likely to boomerang in any respect, in terms of information, uh, coming back though a third party… "* (Participant 7). Another participant commented that without anonymity, they would worry about 'social repercussions.' Other participants simply felt that anonymity was important to them.

Interestingly, two participants said that personal anonymity was not a concern. For one participant, retirement and the subsequent anonymity from the workplace negated their worries about others knowing about their disease. Another participant, who was diagnosed with depression, felt that a lack of willingness on the part of individuals with PD to be completely open about their illnesses with family and others may unintentionally cause harm both to themselves and the people that are seeking help to cope with their own depression (Participant 14). As the participant mentioned, "*I can't see the point in covering up the health problem, like if you share it, it can be solved a lot better*" (Participant 14).

4.2 Sources of knowledge about online information safety

Participants described a number of ways they learned of the possible risks and problems with online information privacy. Two main sources related to information privacy security issues were: (1) media reports, and (2) family and friends.

4.2.1 Media Reports

Participants identified a variety of media sources as influencing their perceptions of online information privacy. Television and newspapers were most frequently identified as a primary source of information about privacy and important information sources that contributed to shaping participants' perception of online information safety, as well as their primary source of day-to-day news.

Participants identified several highly publicized 'scams' involving a breach of information privacy. Two participants made reference to Julian Assange or the WikiLeaks problem (http://www.ted.com/speakers/julian_assange.html) and another participant spoke of the *News of the Word* tabloid telephone hacking scandal (http://www.thestar.com/news/world/article/1019672--u-k-tabloid-phone-hacking-scandal-takes-a-sickening-turn). There were also references made about unspecified instances of information exploitation specifically targeting the elderly. When discussing information privacy, participants tended to link all scams and privacy breaches together. Participants made reference to pedophiles on the Internet, financial scams on the Internet, and various stories about Internet dangers, all of which were heard or seen through the television or newspaper. One participant summarized how she learned of the dangers of the internet and information privacy concerns in this way:

> *The other things is that one day last week, there was something on T.V. where, you know, the pedophile go to meet up with somebody that they think is, is, very young and they know it, and the police arrest them, and... that kind of show. ... I'm counting on the newspaper, occasional use, and the television* [for information] (Participant 8).

In this case, the police sting operation had involved police pretending to be 'prey' on the internet, which the participant linked with the spread of personal information and privacy breaches on the internet. To the participant, therefore, learning about the 'pedophile sting' contributed to her understanding about online information privacy concerns, and the newspaper and television were her source for doing so. Participants did not differentiate the type of information breach (e.g., the News of the World involved hacking into telephone data, not Internet breaches) but rather linked all examples of information breaches to the safety of online information privacy, even when they had little to do with Internet privacy at all, such as the News of the World *telephone* hacking scheme.

It is acknowledged that the 'privacy breach' media coverage at the time of data collection may have been reflected in participants' perception of information privacy. The same respondent who suggested that this media coverage affected her views on privacy suggested that *"as I say, because this thing I was on about WikiLeaks last night, and last week was the thing about the pedophiles, and this morning the hackers from the news of the World, it's just a little – just a little bit you know, higher in my blood. Normally I'd probably just talking about singing along with, um, Marty Robbins on YouTube!"* (Participant 8).

4.2.2 Family and Friends

Stories of family and friends' experiences with information privacy breaches were important influences in participants' perception of online information privacy. Participants related that 'privacy breach' stories from family members and friends created an awareness of privacy concerns, and although some of the information scams did not involve the Internet, they collectively contributed to the participant's view of Internet privacy. For example, one participant cited how a friend was called with a request for bail money for the friend's nephew, who was allegedly locked in a Mexican prison. The friend later found out this was a scam. By telling the participant this story, the *friend's* realization or experience with privacy became adopted into the participant's own narrative about privacy, and, in this case, became related to their perception of privacy on the Internet. Similarly, one participant's daughter had experienced a privacy breach on the Internet which resulted in action taken by both the police and lawyers. Another participant told a story of a brother who was able to find a picture of her house on the Internet, simply by typing in her address; another participant spoke of 'Google-ing' her name, and finding personal information that she had not consented to release:

> *"I did G... Google myself once, at my, my friend's, you know, we were just sort of fooling around, and, uh – he said to me, well, let's Google and see, see what they've got down about you. And it was amazing, the amount of information that they had, information which I had never given out."* (Participant 4)

In each case, this created a 'sudden awareness' experience, which changed the way participants perceived information privacy on the Internet.

The privacy breach experiences of family or friends were important 'learning events' for participants and produced a sudden realization about the vulnerability of their online information or a recognition of the extent to which their personal information already existed on the Internet. The experiences of family members and friends became a part of the participant's own perception of privacy.

4.3 Reasons for privacy concerns

Another theme that emerged were elements that prevented, reduced, or affected participants' online use, or changed the way they perceived privacy. The findings reported here form the reasons for privacy concerns and include: the mystery of the net, *"Gaggle", "UPS" numbers, and the "wookie links" guy.*

The inability of participants' to understand the Internet, and how the Internet functions, contributed to their concern and worry about information privacy on the Internet. One participant was taken aback when a website she visited identified her IP (Internet protocol) address; the confusion over this was embodied by her vocabulary:

> *"And a little bubble came up, and it said, uh, my IPS number and such and such, and I thought, holy cow – you know, how is it that they can read that?"* (Participant 8)

This participant initially referred to the IP address as an IPS number, and later referenced it as a UPS number (which generally refers to a number used to track packages in the mail) and mentioned how 'they' can track her on the Internet using this number. The participant then summarized her computer and Internet knowledge as that of a 'user' and provided an analogy of her internet knowledge using several examples:

> *"Because it's like... we can – you and I can drive a car, but that doesn't mean that I could fix the engine – I took a course once, but that doesn't mean I could fix an engine – I can switch on the electricity to make my air conditioner work, but that doesn't mean I could make one... and it's the same with the Internet. The Internet is one of the most humbling systems around, especially for – I'm not, I'm way behind as far as using machines go, but for my age group, I'm pretty darn good."* (Participant 8)

Although, as her analogy implied, she could make use of the Internet, the *how* of the Internet still bewildered and confused her.

Similarly, one respondent mentioned how she once used "*Gaggle – Google – something like that,*" and another participant identified WikiLeaks as *"Wookie leaks"* in their discussion of online privacy concerns. These vocabulary inaccuracies exemplify the mystery that many participants felt with the Internet; participants expressed puzzlement and confusion about the Internet, referencing their lack of Internet skills and bewilderment at the prodigious and easy use of the Internet by younger generations. Participants expressed both frustration at the mystery of the Internet, and also suggested that the mysteriousness contributed to worries about their privacy. Participants suggested that they knew that others on the web could affect them through the Internet, but did not understand the mechanism through which this could happen. One participant stated that

> *"the accessibility of the general public of anything that's on the internet worries me, because, uh, there's so many things that people put on the internet and think that, okay, fine, well, it's there, and it's, it's okay. But who knows when some kook is going to come along and use it for something that it was never meant for at all."* (Participant 4)

This lack of knowledge about how, and by whom, their information could be used, caused participants fear and worry about their online information privacy.

4.3.1 Physical vulnerability and privacy concerns

Age and illness was noted as altering participants' perceptions and concerns about online information privacy. Two respondents mentioned that their Parkinson's disease made them feel more *physically* vulnerable, which in turn caused them to worry about the ability of those with nefarious intent to track them down through the Internet. One participant told of how a simple handshake could knock him over, while another aligned her physical vulnerability to her concern about Internet privacy breaches. She stated that:

> *"And... because my walking is getting bad, and I often use a cane, I'm aware of feeling unsafe physically, you know what I mean? So that I don't go out at night in downtown ..., and I'm just aware that somebody could knock me over very easily... that's the same thing here, at the house. If somebody could get a picture of my house – now, it's very modest, and I don't think robbers would come, but you never know. So it's physical*

> *safety, it's, um, just knowing that there might be some way that they could make use of this address for identity theft, or something like that."* (Participant 8).

Privacy breaches on the Internet therefore became more threatening, as participants no longer felt they had adequate physical strength or ease of movement to protect themselves. This physical decline made them feel more vulnerable as targets for delinquent activity, which they believed could be planned with personal data gleaned from the Internet. As well as physical limitations, mental limitations also played a part in influencing privacy concerns; one participant's tendency to forget things made him concerned about doing anything that involved private information on the Internet (such as online banking, etc.).

4.3.2. The lack of "people" on the net

Trust, within this participant group, was often linked to face-to-face communication. Using the Internet means that trust is difficult to establish, because one is 'talking to a screen,' not to a person. In essence, *"... you'd be sitting there, looking at a screen, putting your messages in and so forth. But – but it's a machine that you are talking to, or that you're communicating with...."* (Participant 4). When it came to disclosure and Internet privacy it was indicated that there was greater comfort in giving out personal information to people that participants knew. 'Knowing' somebody, however, required a face-to-face meeting.

4.3.3 Attitudes towards privacy and disclosure

Two participants characterized themselves as naturally 'private' people. They stated that they would be uncomfortable sharing personal health information online as they rarely even shared this information with close friends or family. One participant explained it as

> *I just, I'm a very private person, and I just don't like to, uh, I just don't like to talk about things, it's just something that I, I, uh... I guess I've just been like that all my life. I think my whole family is the same way... we don't even tell each other if we are sick, you know?* (Participant 6)

This private demeanour affected their normal, day-to-day interactions with friends, family, and acquaintances, and both participants identified it as also affecting their comfort online.

By contrast, other participants did not consider themselves to be 'private' people, and as one participant stated, "*I share my feelings, I'm not private at all*" (Participant 14). This self-identification tended to align with how much personal information people would be willing to share on the Internet. As one participant indicated

> *Its people who've got something to hide ... people that are ashamed of themselves.... they've done something wrong, or they're very negative, I don't know. But it's... for me, it's not a problem... I tell the truth, I've got nothing to hide, nothing to be ashamed of... I... I don't like people who lie, and I don't do it myself.* (Participant 10)

For this participant, however, there was still one exception to his lack of worry about privacy of information on the Internet, for as he mentioned, "*I will not disclose any personal information as far as bank accounts are concerned on the Internet. That's not the place for – that's not the way to do it.*" (Participant 10).

4.4 Non-privacy related reasons for not using Internet resources

The individuals interviewed in this study had not participated in online Parkinson's communities, support groups, chat groups, forums, or discussion boards, although they had accessed the Internet at least once. Although one of the participants had little experience on the internet besides a handful of Google searches, the participants in general had made regular use of an e-mail account, Google and/or Youtube. Besides their stated concerns regarding information privacy, participants also provided additional reasons for their limited online presence as: (1) distaste or discomfort with the Internet; (2) not knowing the resources were out there; and/or (3) having all their needs currently met.

4.4.1 Discomfort with the Internet

Participants' limited use of online Parkinson's communities was, in part, attributed to their lack of computer and Internet skills, or a lack of comfort when using the Internet. When asked what would have to change for them to use Internet based resources, such as Internet-based PD communities, it emerged that participants felt they would require better and more comprehensive computer skills. For example, to participate in an online PD community, one participant stated that:

> *Well, for one thing I'd have to, um, learn how to use it ... because I have tried, I've taken a couple of computer courses to sort of get the, to try and find out how to do this - and I, I just find that I don't get it very well.* (Participant 4)

One participant who considered herself to be relatively Internet-savvy stated that most people of her generation would not be familiar with how to use YouTube, or know that 'cookies' on the Internet could be potentially dangerous. Although participants noted that they worried about their information privacy when online, it emerged that participants could not describe steps that they could take to secure their online privacy, beyond keeping passwords confidential.

4.4.2 Lack of Awareness

One theme that emerged was that participants were unaware that online support groups existed, and that there were Internet-based communities available. Participation in an online PD community "*just doesn't come to mind... it's just not part of my thought process, I guess.*" (Participant 7). Participants expressed this lack of awareness when asked why they had yet to make use of an online PD community (chat board, forum, discussion group, support group, etc.)

4.4.3 Having all needs met

Participants also suggested they were content with the knowledge and support gained through in-person support groups, their doctors, their family, or other supports, and there was no need for them to try Internet-based resources. One participant mentioned that

> *I just, I don't see myself saying "Gee, you know, maybe I should go online and see what's out there in forums and discussion groups and try to participate in one'... at the present moment I am satisfied, it wouldn't really give me any better understanding of where I'm at, where I could be headed, than I have right now.* (Participant 7).

It was acknowledged that if their mobility problems worsened (e.g., making them unable to maintain their current lifestyle), then perhaps participants would look to the Internet for PD-related support. The internet, it was thought, could be used at their own pace, and although potentially difficult to use with tremors and so on, would be still easier to access than in-person groups. However, there had to be a need, beyond curiosity or the need for personal health information support, before they would resort to the Internet. Participants were inclined to view personal support as a face-to-face activity, whereas online resources were used for gathering facts about PD. One participant stated, that when online, "*I don't want any of the back and forth chat – that would be irritating to me... It's, it's the typing, it's so much slower than talking... and, um, as I say, the confidentiality is a big thing for me.*" (Participant 8). In-person meetings were seen as the preferred method for emotional support, unless physical limitations hindered their ability to do so. The Internet was, instead, seen as a resource to access papers and information from professional sources such as the Mayo clinic and health care professionals.

CHAPTER 5: DISCUSSION

This study investigated the perceptions of information privacy held by individuals with PD with regards to the Internet and Internet-based PD resources. Participants' views on information privacy appeared to be strongly influenced by mass media reports and by close family and friends. Their perception of privacy on the Internet is coloured by media coverage of information scams and privacy breaches, regardless of whether these incidents occurred on- or off- line. To participants in this study, maintaining their online privacy meant safeguarding financial, family, sexual and health information (including information about their mental health) except if sharing their personal information could help others. The study findings also indicate that participants lacked awareness of online PD support communities, with online resources seen simply as factual sources and not as a source of personal or social support. The limited utility of online PD support groups was attributed to: (1) the 'people-less' state of the Internet, and (2) a perceived lack of computer skill, combined with the Internet being seen as mysterious and confusing. This confusion created fears about information privacy and privacy breaches while online.

How do these attitudes and perceptions compare with the general population of seniors without PD? Participants in this study had an average age of 73 and their use of the Internet varied, from those who used it daily to those who used it several times a year. Participants frequently mentioned using email and search engines as components of their Internet use. This result is not surprising, relative to the findings of an international study that reported 87% of the individuals aged 65-73 who made use of the Internet used search engines, and that 75% of those 50 years of age or older who made use of the Internet checked an e-mail account at least once a week (van Eimeren & Frees, 2010, as cited in Maaß, 2011; Zickuhr, 2010).Of American adults who are online, the number of adults aged 65 and older who made use of social networking media such as Facebook, however, was half that of the number of adults aged 50-64 using online social media technology (Madden, 2010). Seniors normally face barriers on the Internet, which can be classified into four categories, namely "intrapersonal, interpersonal, structural, and functional" constraints (Lee, Chen, & Hewitt, 2011, p. 1). Comparing seniors of different ages reveals that the experiences of all individuals 65+, and the extent to which these barriers affect them, cannot be generalized; increased age amongst those 65+, was, for example, correlated with increased stress in uptake of Internet technology, as well as increased functional difficulties (e.g. mental and cognitive impairments), and a smaller social network that would not allow for help in using the Internet (Lee, Chen, & Hewitt, 2011; Statistics Canada, 2007). The findings in this study align with these results, where participants discussed both technological difficulties and physical and mental impairments as reasons for their lack of Internet community use. It is also not surprising that the majority of participants in this study were worried about privacy on the Internet, considering that 85.7% of individuals over 55 years of age reported sharing that concern (Burst Media, 2009).

Participants in this study demonstrated that their perception of privacy on the Internet included the expectation or desire for anonymity. In studying 14 well-trafficked general online communities for seniors (websites with forums and/or chat rooms, etc. for discussing retirement, family, entertainment, and so on) it was found that anonymity was a frequent feature of these often-visited general online communities for seniors (Nimrod, 2010). This suggests that the emphasis put on anonymity when online by individuals with PD may be quite in-line with their age group. Along with anonymity, the results demonstrate that confidentiality also plays a role in the privacy perceptions of participants. According to a survey of 2001 Canadians over the age of

16, linking confidentiality to privacy is a connection made by 1 in 3 (32%) Canadians in 2007, whereas in 1999, only 18% of Canadians mentioned confidentiality concerns when asked about privacy (EKOS Research Associates, 2007). The link between privacy and confidentiality in the results of this study is therefore not surprising. The Canadian census administered in 2009 found that individuals who had used the Internet for five or fewer years were more likely to be worried about the privacy of their financial information, including use of credit cards and online banking, than those who had used the Internet for five or more years; this trend towards adopting email and information searching, but avoiding online banking and shopping, is particularly prevalent amongst seniors (Fox, 2005; Statistics Canada, 2009). It may be that the participants in this research study who were worried about the privacy of their financial information are individuals who only recently became Internet users. Although some participants may have been exposed to computers for years, especially for work, several participants noted that they had only recently started to make use of the Internet. The worry exhibited by participants about financial privacy on the Internet conforms to that exhibited by other 'inexperienced' senior users.

In looking for tips about coping and support, participants in this study expressed a preference for face-to-face meetings and interactions, often seeing the Internet instead as a source for 'fact-finding' in searching for PD information. Findings from the current study support existing evidence that finds older adults (65 years and older) more likely to approach a health care professional, such as a physician, about coping strategies and dealing with the day-to-day stresses of chronic disease, than are younger adults ($\leq$64 years of age), who are more likely to approach family, friends, or fellow patients (Fox, 2011). It is interesting to note that on the PatientsLikeMe© PD community (http://www.patientslikeme.com/), the demographics statistics of the 5,772 members (as of September, 2011) demonstrates that the 60-69 year old age group is the most prominently represented, followed by the 50-59 year old age group (PatientsLikeMe, 2011). The 70+ year old age group is the third largest age group, and is nearly matched by the amount of members aged 40-49. In surveying 1323 PatientsLikeMe© members from six different PatientsLikeMe© communities, including the PD community, researchers found that Parkinson's patients exhibited the highest levels (similar to Fibromyalgia patients), of discomfort with health information sharing (Wicks *et* al., 2010). It is possible, therefore, that the lack of impetus to go online and search for or use PD communities is characteristic of individuals with PD, and possibly associated with their age. Their preference for face-to-face interaction, when combined with the age-correlated tendency to look to health care professionals rather than fellow patients in searching for coping strategies, might explain the lack of desire among the participants in this study to search out online PD support communities.

Whether seniors, in general, fear physical vulnerability as a consequence of breaches to online privacy is a question that has apparently yet to be answered within the literature. Participants in this study expressed fear that breaches of their information privacy (e.g., knowledge of their physical disability, pictures of their house being found through satellite imaging services such as Google Maps) – when combined with the physical limitations characteristic of PD (postural instability, limited mobility, etc.) could render them more personally vulnerable to crimes on their own property. In elderly individuals, frailty can approximate many of the same physical disabilities and limitations of PD (Ahmed, Sherman, & VanWyck, 2008), and elderly individuals may encounter physical limitations due to a wide range of causes, including advanced age. Whether these individuals make the same connection between online privacy and physical vulnerability, however, is unknown, but may have implications for future research to explore the perceived value and use of Internet-based healthcare and health resources in the future.

Participants felt that the 'lack of people' on the Internet limited their participation in online support communities and use of the Internet as a source of PD information. This phenomenon had consequences for uptake of online PD resources. For participants in this study information about health and PD support was most comfortably shared with people they could physically engage with. In effect, participants claimed that knowing a person allowed them to trust the person. 'Knowing' a person comes from meeting them, often several times. However, participants in this study mentioned that they didn't view contributing to online communities or chat forums as 'meeting' people. Instead, they felt that there was a 'lack of people' on the Internet and expressed difficulty engaging with a machine, rather than directly with other people. For this group of older PD clients, limited computer skills and a lack of opportunity to physically meet within online communities created a barrier to the use and utility of online PD support communities. This phenomenon appeared to be linked to a cascade of events whereby the lack of opportunity to meet and get to 'know' people on the Internet impedes the development of a trusting relationship, leading individuals with PD to be wary of sharing information and participating in online communities of support. Dwyer, Hiltz and Passerini (2007) found, however, that building social relationships over the social networking sites Facebook© and MySpace© actually did not require trust, which contradicted the building of relationships in face-to-face interactions, which do require the creation of trust. As the participants of this study expressly connected an inability to trust over the Internet with an inability to form relationships via the net, the finding here contradict what would be expected, based on Dwyer, Hiltz and Passerini's work. It is possible that the difference in ages between the participants of this study (average age of 71) and the participants of Dwyer, Hiltz and Passerini's study (average age 20.3 for the Facebook users, 22.93 for the MySpace© users), along with the accompanying differences in use and comfort with the Internet (participants in this study were fairly uncomfortable with the Internet and were largely inexperienced Internet users), might contribute to this difference in results.

Worries around privacy breaches on the Internet seemingly exacerbated concerns around physical vulnerability. This research provides preliminary data linking online information privacy concerns of clients with progressive physical decline with decreased use of the Internet as a resource for information and support. Further research is needed to explore how the self perceived physical vulnerability of older Canadians with PD influences Internet use, especially as these concerns of physical vulnerability due to the spread of online information may not be unfounded. For example, researchers in the U.S. were able to accurately assemble the first five digits of the social security numbers (SSNs) for 44% of the individuals on the U.S. DMF (Death Master Files) from 1989 to 2003, by statistically cross-referencing the state of birth and date of birth of individuals, gathered from publicly available information, such as voter's lists, online white pages, and online social profiles, with an analysis of a publicly available death records database (Acquisti and Gross, 2009).The researchers suggest that this method could be extrapolated easily to find the SSNs of millions of living Americans, highlighting how publicly available data easily yields data that is thought to be private and secured (Acquisti & Gross, 2009). Although this research does not specifically address consequences for Canadians, it does serve to demonstrate the disturbing potential of how information currently existing online can be manipulated. The targeting of seniors by consumer-based scams, and the physical vulnerability felt by seniors when using online health care will need further investigation. Online information resources will need to address clients' information privacy concerns. Possible solutions involve additional mentoring or educational programs to help address the worries of these individuals, or instituting scam-protection software on seniors' computers to prevent data phishing (Chakraborty, Rao, Sankaranarayanan, & Upadhyaya, 2008; Voelker, 2005; Wagner, Hassanein, & Head, 2010). In addition, individuals with PD can be subject to mental deterioration or confusion as well as being prone to impulse control disorders that occur as a complication of PD treatment; these disorders can lead to behaviours such as compulsive gambling or shopping (Ceravolo, Frosini, Rossi, & Bonuccelli, 2010). With a growing awareness of impulse disorders as a complication from PD treatment, additional research is needed to determine how mental status among individuals with PD affects their concerns and behaviours related to online information privacy and perceived vulnerability.

Participants defined private information as containing family, financial, and sexual information, with a range of responses about whether health information should or should not be considered private and under what conditions. Although identity theft was mentioned in passing when discussing concerns, in general, participants' concerns regarding information privacy were related to the anonymity surrounding Internet use, as well as the fear of strangers using the participants' online information for malicious purposes. Education about what the actual dangers are of releasing information on the Internet – not just financial scams, but knowledge about the participant's day-to-day habits, health information, etc. – may be of assistance both to address worries in which the risks and benefits can be better defined (for example, online banking) and to discuss the risks (e.g. identity theft, dispersal of health information) of which individuals with PD do not seem to be as aware. It is also interesting to note that although participants expected anonymity on the Internet, they did not perceive the Internet as a safe place to freely share personal information. These results stand in contrast to research suggesting that Internet anonymity allows for a dis-inhibition effect, or easier self-disclosure of personal information, including health information otherwise seen as personal or embarrassing, to strangers through the Internet (Bargh & McKenna, 2004; Suler, 2004; White & Dorman, 2001).This discrepancy is possibly a reflection of other factors that affected the participants' concerns over Internet privacy, including their difficulty in creating trust online and confusion over how the Internet works; as mentioned, participants felt trust could only be established through face to face contact, and participants would use the Internet but frequently found themselves baffled as to how the Internet actually worked. While participants may expect online anonymity, the lack of 'real people' online and limited understanding of how the Internet works, may have prompted a cautiousness in participants related to sharing their personal information online.

It is worth noting that previous research has discussed the optimism bias, or the tendency of individuals to underestimate the risk to themselves of privacy breaches online and underestimate the size and scope of the Internet's reach (Acquisti & Gross, 2006; Cho, Lee, & Chung, 2010; Ngeno, Zavarsky, Lindskog, & Ruhl, 2010). In this research, participants did seem to have concerns about privacy breaches, and to be aware of and concerned about risks to themselves. Their expressed behaviour, however – as in, the steps that they suggested they would take to maintain their privacy was more in keeping with the optimism bias, as participant security precautions were often minimal, consisting of little more than ensuring that their passwords were kept secret.

Canadian privacy policies

Despite the in-depth discussion by participants concerning information privacy on the Internet, there was no participant mention of governmental policies to protect the online privacy of Internet users. Although worrisome, this appears to be a common Canadian trend. A recent survey of 2,001 Canadian adults (16 years of age or older), for example, revealed that over half of the respondents reported having no knowledge or awareness of current privacy policies (EKOS Research Associates, 2007). The Privacy Commissioner of Canada's newest report on PIPEDA has also identified public privacy literacy as an important area that requires improvement in Canada (Office of the Privacy Commissioner of Canada, 2011). Similarly, concern about Canadians' low level of knowledge about information privacy rights and protection is addressed in the *Report on Plans and Priorities 2011-2012*, which has set the goal of having 20% of Canadians aware of both the function of the Office of the Privacy Commissioner (OPC), as well as ensuring that 20% of Canadians have an 'average' awareness of their information privacy rights by the end of 2012 (Office of the Privacy Commissioner of Canada, 2011b; EKOS Research Associates, 2007).

The findings from this study support previous research regarding consumer ignorance of online information privacy policies. It is not surprising that the participants of this study did not discuss the protections and rights provided by privacy policies such as PIPEDA or PHIPA, when discussing their privacy on the Internet. It may be that direct questioning about privacy policy awareness would have yielded different information from participants. However, inquiry about how participants protected their online privacy, and researcher questioning about what they thought when they heard the phrase "privacy on the Internet," did not yield any mention of government-legislated privacy protection; this is perhaps indicative that the participants in this study belong to the 80-plus percent of Canadians who display below average knowledge about privacy rights and protection. Regardless, the absence of participant discussion regarding legislation, protection, or the rights of Canadian citizens, with regards to online privacy, supports the suggestion of a gap in public awareness and education that needs to be remedied.

The impact of the media

The results of this research are inherently linked to the environmental context of the time period during which the research occurred. The extensive media coverage on information privacy and security breaches suggests that the time period in which the interviews took place (April 2011 to July 2011) may have influenced participants' thoughts about Internet security and information privacy. During this time period, for example, there was intense media coverage of the Julian Assange and his alleged participation in the WikiLeaks scandal; the *News of the World* phone-tapping scandal; stories about the first 'swatting' attacks by hackers in Canada; and debate over the new Facebook facial recognition system, amongst others.

The mass media plays a significant role in consumer health education; older adults in particular rely on physicians, and then on media sources such as newspapers, magazines and television for their health information needs, rather than depending on the Internet for health information as younger adults do (Detlefsen, 2004; Tian & Robinson, 2008.) Driven in part by the development of online social networks, the number, scope, and sensationalism of media stories on information privacy breaches have dramatically increased; between 1993 and 2001, for example, newspaper, magazines, and trade publications were found to exponentially increase their coverage of privacy issues (Roznowski, 2003). Increased, or inflated media coverage of information privacy scams are influential in shaping consumer perception of information privacy and security, and participants in the current study reported that the mass media was a significant information resource influencing their understanding of online information privacy. However, the Information and Privacy Commissioner has also been receiving record levels of privacy appeals and freedom of information requests, and, in the most recent report, showed that the year 2010 set a record for the greatest number of privacy complaints in one year (Information and Privacy Commissioner, 2011). In short, the increase in privacy incidents, and media coverage of those instances, points to the strength of the mass media in shaping consumer understanding of online information privacy. As the Internet becomes increasingly pervasive as a health care management tool, health care educators and providers might strive to better leverage mass media strategies to develop consumer awareness and understanding of information privacy among older individuals with PD.

Methods

In the methods and results sections of this study, the difficulty in finding individuals who had PD and made use of Internet-based PD support groups was noted. Based on data from the Canadian Internet use survey from 2007, 48% of Canadian seniors (those aged 65+) were engaged in organizations within their communities, but only about10% of Canadian seniors used the Internet in joining or participating in such groups (Veenhof & Timusk, 2009). This means that many more individuals of the 65+ age group were involved in their communities, as compared to other age groups, but fewer of this 65+ age group used the Internet to facilitate this involvement (Veenhof & Timusk, 2009). Similarly, 18% of American adult Internet users aged 50-64 have searched online for other communities of individuals with similar health conditions, compared to 10% of those aged 65+; however, in both cases, approximately 23% of each age group are actually caregivers searching for online communities and online support (Fox, 2011).

Considering the average age of individuals diagnosed with PD, the seeming lack of research participants could reflect the select group of individuals fitting the inclusion criteria of a PD diagnosis and online support group participant. In future research, it would be informative to clarify the characteristics of those who participate in online PD communities, and determine the unique information and support needs of these different user groups.

Study limitations and future research

There are limitations to this research. First, information on participants' disease co-morbidity and specific disability was only collected if the participant chose to discuss this in the course of the interview. Although participants were asked about using the Internet for health care reasons beyond PD, researcher inquiry was not specific to participants' co-morbidities or disability as an influence on their potential use of the Internet. Although other illnesses and disabilities were recorded through the interview process (strokes, broken bones, surgeries, depression, etc.) the scope of this research did not allow for a numbering and comparison of co-morbidities. Co-morbidities may, however, change the results; for example, within the literature, it is known that in Canadian seniors, hearing difficulties alone are linked to lower use of information technology (Gonsalves & Pichora-Fuller, 2008). Further research on this topic would therefore benefit from comparing the effects of co-morbidities and disability on the privacy perceptions held by individuals with PD.

Secondly, this study included volunteer participants who were all diagnosed with late onset PD, rather than having a mixture of those with late-onset and those with early-onset. This exclusion was not intentional, but having individuals with young-onset PD as participants may have highlighted different issues with regards to concerns and perceptions about information privacy. Research comparing information privacy issues between late-onset and early onset individuals with PD would provide a more comprehensive assessment of information privacy issues among individuals with PD. Less likely to be novice Internet users, an investigation of online information privacy with early-onset PD participants would allow for a greater understanding of information privacy issues among a wider cross section of PD clients.

It has been mentioned that beyond individuals living with chronic conditions, the other large user group of online PD resources and support communities are the informal caregivers (e.g., family and friends of those with PDs). Comparing the results presented here with a study on the perspectives on privacy held by the informal caregivers of individuals with PD would give a fuller understanding of the privacy perceptions of those who might also make use of online PD support communities. In consideration that many individuals with PD relied on spouses or caregivers to find or retain information, as well as the emotional support needed by caregivers themselves, the perceptions of caregivers on online PD resources and support will be equally influential in creating and maintaining appropriate and useful Internet resources. Similarly, extending an investigation of online information privacy to all family members of those with PD might help to elaborate on the use of online PD resources and communities. Several participants of this study suggested that they rely on younger family members to check Internet resources, and the perceptions of privacy of those family members may be equally useful in developing future online PD resources.

As this study was limited in scope and number of participants, as well as being limited to those living within south-western Ontario, future research with a greater number of participants from a more geographically diverse area may provide different or greater insights into the perceptions of privacy held by individuals with PD. With the broad categories and issues identified here, future investigation into this subject with quantitative methods and a large number of participants would allow for broad, generalizable results which could not be yielded from this qualitative research.

Conclusions

The results of this study demonstrate a number of worrisome aspects of the privacy perceptions of individuals with PD that need to be attended to in order for older Canadians with PD to make full use of Internet-based healthcare resources. First, the lack of participant discussion linking online privacy and the legislated online information protection and privacy rights is troubling. This is particularly important in light of the prevalence of privacy concerns among this particular group, and their worries over using the Internet. There appears to be a gap in consumer awareness of the policies in place to protect online privacy. Secondly, the link between self-reported physical vulnerability due to PD, and privacy concerns about using the Internet, requires further investigation. Currently, we fail to address feelings of *physical* vulnerability in those with PD while using the Internet. Attention to this matter may assist in the uptake and use of online resources to support the care of older Canadians managing PD. Thirdly, the perceptions of individuals with PD on Internet privacy are formed through the media, family, and friends and although these might prove to be excellent resources, other authoritative sources such as the Office of the Privacy Commissioner of Canada do not seem to be well-recognized among older individuals with PD in this study. The Office of the Privacy Commissioner has invested in the development of educational tools for the public and perhaps greater investment into the marketing of this information may be warranted.

Finally, continued investigation into the development of safe and useful online health resources for individuals with PD is needed. It would be prudent of resource developers to bear in mind the perceptions of online information privacy of older individuals with PD. With growing numbers of health care consumers turning to the Internet for information and support, and the fiscal challenges of supporting a health care system serving a population with an aging demographic profile, there is a real need to create safe and user-friendly ways for individuals with progressive chronic diseases such as PD to gain support and knowledge through the Internet.

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APPENDIX A: Interview Guide

Ask for permission – recorder. Turn on recorder. Go through letter of information, consent. Answer any questions.

What are these individuals aware of, with regards to their privacy, when using these online PD support groups?

1. Year of birth?
2. Can I ask how you were recruited to this study?
3. Can I ask how long it has been since you were diagnosed with Parkinson's?
4. Have you ever made use of the Internet?
    a. *No: does not meet inclusion criteria*
5. Do you have access to a computer and Internet in your home?
    a. No:
        i. Do you have access to a computer and Internet elsewhere?
6. How often do you make use the Internet?
7. What do you typically use the Internet for?

8. Have you ever used an online Parkinson's support group, chat or discussion board, or forum?
    a. *Yes: continue interview, but interview will be excluded for not meeting criteria.*
    b. No:
        i. Can I ask why you have not made use of an online PD support group, etc.
        ii. Do you currently use an in-person support group or other Parkinson's group?
            1. Can you tell me a bit about your in-person support group?
            2. Can you tell me about what you know about Internet-based Parkinson's support groups, chat or discussion boards, and forums?
            3. What is the difference for you between an in-person and an online support group?
                a. With regards to privacy?
        iii. Would you consider using an online support group in the future?
            1. What would need to change for you to use one? (Privacy)
        iv. Have you used the Internet for any other health-related uses?

9. What type of information would you feel comfortable sharing with an online support group?
    a. What type of information would you definitely not share?
    b. Is this different from what you would share with an in-person support group?
    c. What do you consider to be 'personal information?'
10. WHO are you worried about with regards to sharing your private data?
11. Has worry about privacy ever changed the way you use the Internet, or stopped you from accessing information?
12. When using the Internet, what does protecting your online privacy mean to you?
13. Do you, in general, consider yourself to be a 'private person'?
14. When you hear the phrase 'privacy on the Internet,' what does it mean to you?
15. In general, when using the Internet, what steps do you take to protect your privacy?

16. Do you think your Parkinson's diagnosis has changed the way you think about privacy?
17. Can you tell me about the experiences that have shaped your views on privacy?
    a. Have you, a member of your family, or a friend ever been subject to a breach of privacy?
        i. Can you describe it for me?
        ii. Did this incident change your perceptions of privacy? Your behaviour? How?

18. Can you explain to me what you would say if you were asked 'what is the Internet?'

SNOWBALL SAMPLE: If you know anyone else who would be interested...

APPENDIX B: Recruitment notice

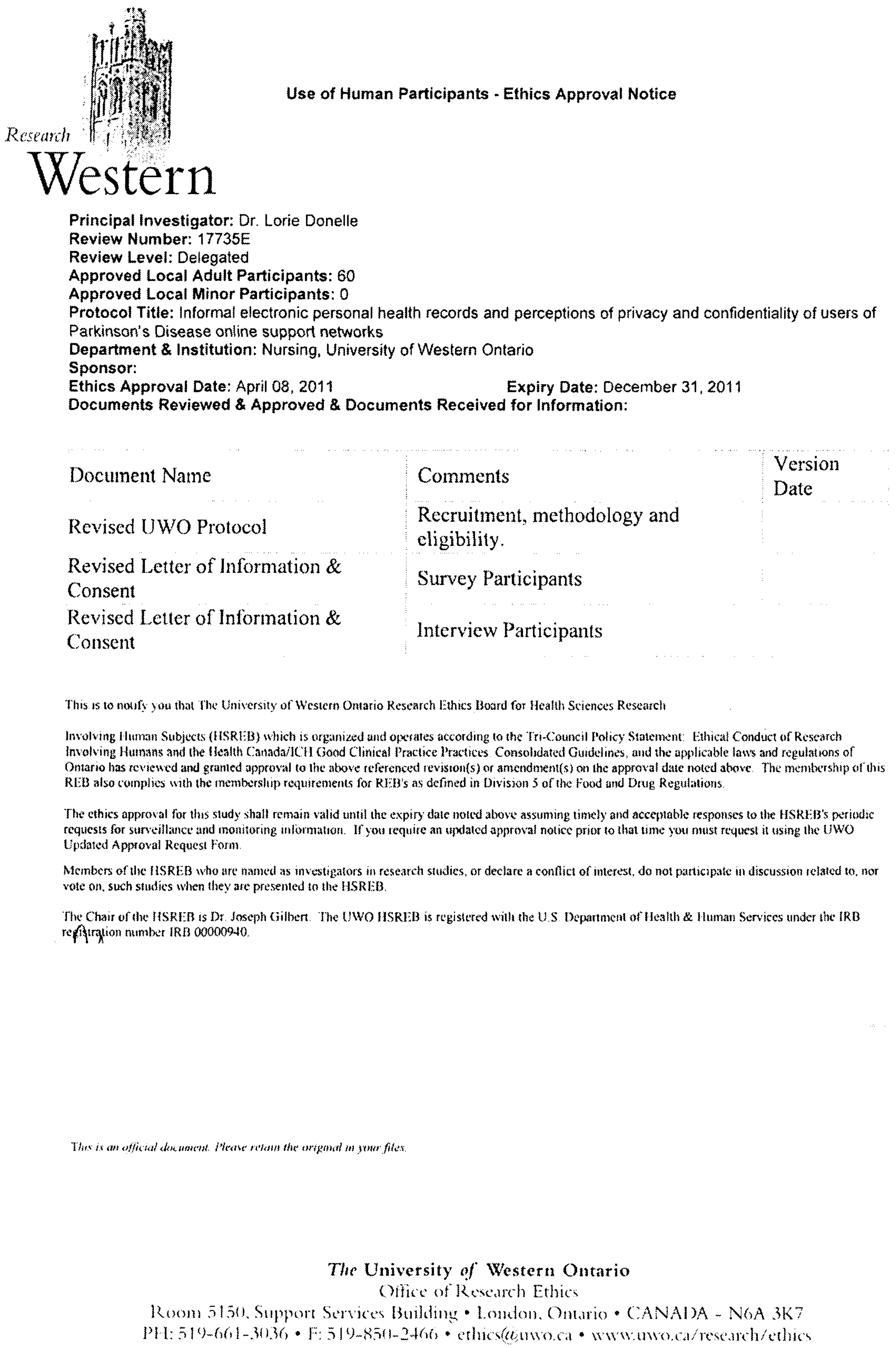
Are you an individual living in Canada who has accessed an online Parkinson's Disease-based support group, forum, online resource, or discussion board, and is interested in participating in a study on your views and expectations about privacy and confidentiality when online?

The main purpose of this study will be to investigate how matters of privacy change the way people make use of Internet-based Parkinson's Disease health care support groups. It is a two-part study. If you are interested in participating in Part A, you will be asked to fill out a short survey either by phone or online. If you are interested in participating in Part B, you will instead be asked to participate in an approximately hour-long interview, which can be conducted by phone or in person.

To indicate your interest in participating, please contact the researcher, Allyson Lee, and indicate in your e-mail or message whether you are interested in participating in either the short survey or the phone or in-person interview.

Any questions about this research project can be addressed to Allyson Lee, via e-mail or telephone.

APPENDIX C: Ethics Approval



Research
Western

Use of Human Participants - Ethics Approval Notice

Principal Investigator: Dr. Lorie Donelle
Review Number: 17735E
Review Level: Delegated
Approved Local Adult Participants: 60
Approved Local Minor Participants: 0
Protocol Title: Informal electronic personal health records and perceptions of privacy and confidentiality of users of Parkinson's Disease online support networks
Department & Institution: Nursing, University of Western Ontario
Sponsor:
Ethics Approval Date: April 08, 2011 **Expiry Date:** December 31, 2011
Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version Date
Revised UWO Protocol	Recruitment, methodology and eligibility.	
Revised Letter of Information & Consent	Survey Participants	
Revised Letter of Information & Consent	Interview Participants	

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research

Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices. Consolidated Guidelines, and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

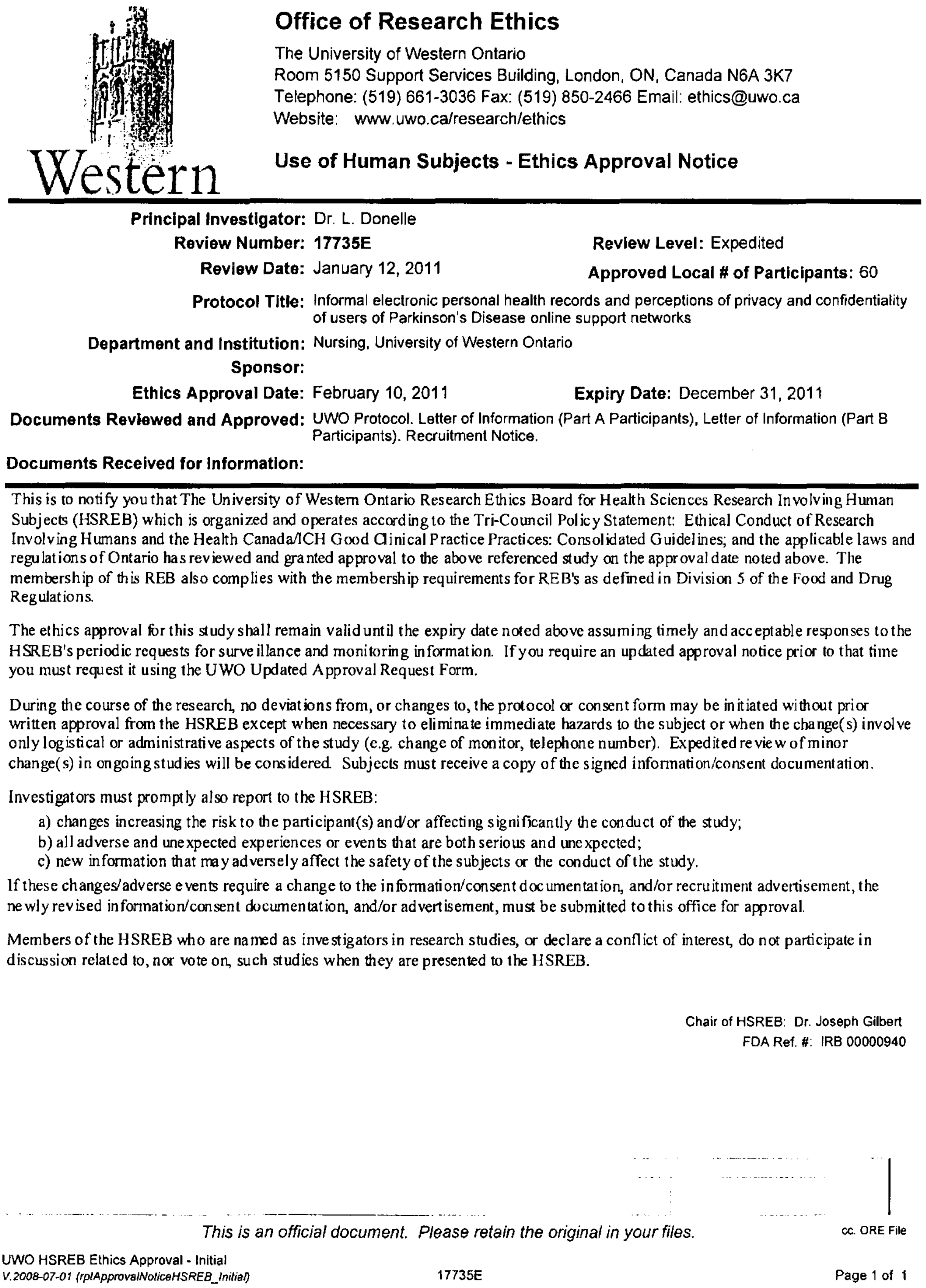
The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The UWO HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

This is an official document. Please retain the original in your files.

The **University** *of* **Western Ontario**
Office of Research Ethics
Room 5150, Support Services Building • London, Ontario • CANADA - N6A 3K7
PH: 519-661-3036 • F: 519-850-2466 • ethics@uwo.ca • www.uwo.ca/research/ethics



Office of Research Ethics

The University of Western Ontario
Room 5150 Support Services Building, London, ON, Canada N6A 3K7
Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca
Website: www.uwo.ca/research/ethics

Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. L. Donelle
Review Number: 17735E **Review Level:** Expedited
Review Date: January 12, 2011 **Approved Local # of Participants:** 60
Protocol Title: Informal electronic personal health records and perceptions of privacy and confidentiality of users of Parkinson's Disease online support networks
Department and Institution: Nursing, University of Western Ontario
Sponsor:
Ethics Approval Date: February 10, 2011 **Expiry Date:** December 31, 2011
Documents Reviewed and Approved: UWO Protocol. Letter of Information (Part A Participants), Letter of Information (Part B Participants). Recruitment Notice.
Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
b) all adverse and unexpected experiences or events that are both serious and unexpected;
c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB: Dr. Joseph Gilbert
FDA Ref. #: IRB 00000940

This is an official document. Please retain the original in your files. cc. ORE File

UWO HSREB Ethics Approval - Initial
V.2008-07-01 (rptApprovalNoticeHSREB_Initial) 17735E Page 1 of 1

APPENDIX D: Letter of Information

Letter of Information and Consent Form – Interview participants

Researcher: Allyson Lee, Master's candidate at the University of Western Ontario under the supervision of Dr. Lorie Donelle RN, PhD University of Western Ontario

Telephone:

E-mail:

Introduction

This study is investigating personal privacy issues or concerns related to Internet use amongst people with Parkinson's Disease. This section of the research project is one part of a two-part study looking at how expectation and concerns about personal privacy shape the way people use Parkinson's Disease Internet support groups and discussion boards.

If you agree to participate in this section of the study, you will be interviewed about your views on personal privacy and Internet support group use.

Research Procedures

The interview will take approximately one hour of your time, and will be audio recorded for use by the researcher. At the end of the interview, the audio recording will be transcribed and identifying information (names, locations, etc.) will be removed.

Risks

The possible emotional, physical, social and economic harms of this study are minimal. Participation in this study may lead you to consider your online security, and your use of Internet support groups accordingly.

Benefits

There is no direct benefit to you from participating in this study. The results from this study may help in the development of future online health support groups and resources that effectively meet the needs of individuals living with Parkinson's Disease.

Voluntary Participation

Participation in this study is voluntary. You may refuse to participate, refuse to answer questions or withdraw from the study at any time. You have no obligation to participate in concurrent or future studies.

Participant Exclusion Criteria

If you have never participated in a Parkinson's online support group, network, discussion board, online resource or forum, or if you do not currently live in Canada or do not have access to an e-mail address, you should not participate in this study.

Confidentiality

Any personal information gathered in the course of this study will be kept confidential. Your name or personal information will not be identified in any documents generated from this research. All data provided will be stored on a secure computer, and back-up files shall be kept in a locked drawer within a locked room, which is only accessible by the researcher. After the study is complete, data will be kept, secured, for five years, after which it shall be destroyed.

Estimate of participant's time and number of participants

The interview should take no more than one hour in total. Approximately 5 to 12 individuals will be asked to participate in a personal interview.

Consent form

You do not waive any legal rights by agreeing to the consent form. To sign the consent form, please type your initials into the statement at the end of this form and e-mail a signed copy of this form to the researcher, or state your verbal agreement to the form.

You are welcome to keep a copy of this letter of information.

Contact Information

If you would like to receive a copy of the final results of the study, please send an e-mail with your name and e-mail address to:

If you have any questions about your rights as a research participant or the conduct of the study you may contact:

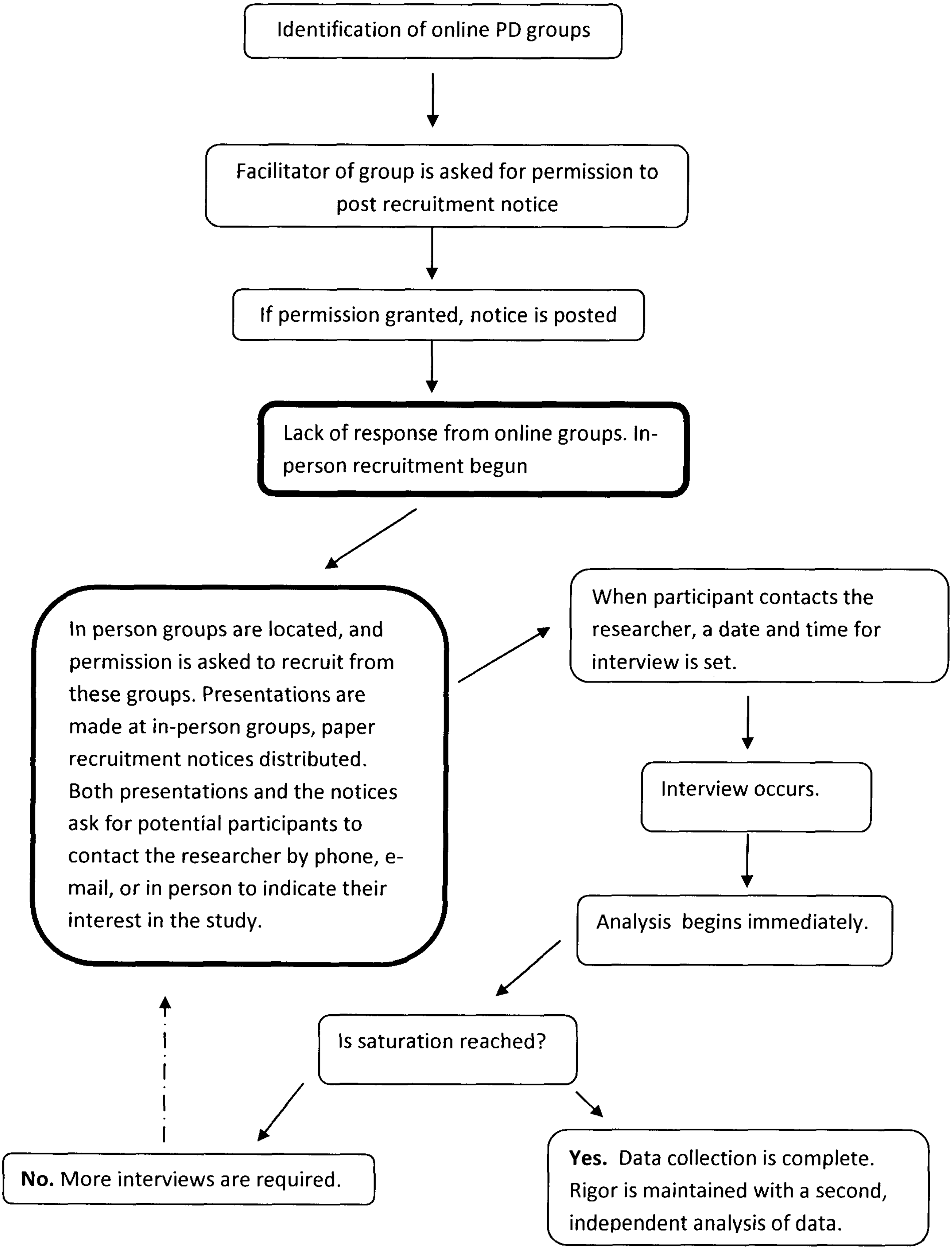
The Office of Research Ethics
The University of Western Ontario

Consent Form

I have read or heard the Letter of Information (or Information/Consent document), have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

Please sign initials here: ________________

APPENDIX E: Methods diagram



APPENDIX F: Canadian Privacy Legislation

Table 2

Canadian Privacy Legislation

Legislation	**Scope**	**Purpose**
Privacy Act, 1985	Federal	Precursor to PIPEDA, deals with personal information (including health information) kept by government institutions (e.g., hospitals)
Personal Information Protection and Electronic Documents Act (PIPEDA), 2000	Federal	Regulates the use, disclosure, gathering and storage of personal information, including health information.
Freedom of Information and Protection of Privacy Act (FIPPA), 1997	Federal	Regulates how public bodies (e.g., government departments, universities) can store and manage personal information.
Personal Health Information Protection Act (PHIPA), 2004	Provincial – Ontario	Regulates not just health records, but the collection, storage, retention and management, and destruction of personal health information