

**Caregiving in the information age: Examining the potential to include service providers in the
online care networks of informal caregivers**

by

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AUTHOR'S DECLARATION

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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ABSTRACT

As the population ages, older adults managing chronic conditions and associated functional impairments will turn to family members and friends to obtain assistive help as informal caregivers. Formal services are often commissioned to provide additional care to complex older adults, creating a network that requires effective information sharing and communication in order to provide optimal care. Unfortunately, important formal-informal care relationships are often not formed and care is not coordinated as effectively as possible. As we enter the information age, services that were once only offered within the community, such as banking and support groups, are now available online. Services now exist to facilitate care coordination for informal caregivers in a shared network of care. Using these tools may show additional benefit if service providers are invited to contribute. Although these tools are currently used by some service providers, there are barriers to gaining widespread user buy-in to this model of use. This study used focus group interviews to conduct a qualitative study on the potential to improve care using an online network to connect informal caregivers and service providers. Case managers, service providers, and informal caregivers were interviewed in order to determine perceptions towards an online network to facilitate communication between caregivers, as well as barriers to supporting online network use by service providers. Interview participants felt that online networks had the potential to improve care delivery through better communication and information sharing, specifically for complex clients who have larger, more complicated care networks. Barriers to the implementation of online networks included the perception that network use would be time-consuming, communication restrictions set by regulating bodies, and the potential for privacy, security, and information ownership issues. Additionally, logistical issues would need to be addressed before the network can be adopted by home care agencies. Widespread inclusion of service providers in online network services will hinge on support from informal caregivers, home care agencies, and regulating organizations. A future pilot study could explore the potential roles and impacts of using online networks to link formal care providers and informal caregivers.

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CHAPTER 1: INTRODUCTION

As the Canadian population ages, the prevalence of age-related chronic diseases will continue to increase faster than ever before, and by 2041 there is expected to be 1.6 million adults over the age of 85 (Public Health Agency of Canada, 2009; 2011). Today, older adults are living longer with multiple chronic conditions, many of which leave them unable to care for themselves (Gilmour & Park, 2006). While home care services are available to help these older adults manage their conditions, allowing them to live independently in the community for longer, the demand for such services often exceeds the availability. Further, when service is provided, it may in fact be inadequate for the client's care needs in terms of time spent with the client and the services provided (Tousignant, Dubuc, Hébert & Coulombe, 2006; Williams et al., 2010). As a result, family members or close friends will frequently provide additional unpaid care, known as informal caregiving. While there is much debate around whether informal caregivers compensate for the lack of services provided through service providers or whether they complement these services, there is certainty about the demand of care placed on informal caregivers (Williams et al., 2010).

Caregiving for an aging loved one has been associated with a number of both beneficial and undesirable outcomes (Aggar, Ronaldson & Cameron, 2010; Baumgarten et al., 1992; Boerner, Schulz & Horowitz, 2004; Butterworth, Pymont, Rodgers, Windsor & Anstey, 2010; Cohen, Colantonio & Vernich, 2002; Fast, Niehaus, Eales & Keating, 2002; Lee, Brennan & Daly, 2001; Tarlow et al., 2004). Research has demonstrated that social support from family, friends and service providers has a moderating effect on the personal costs of caregiving (Schaefer, Coyne & Lazarus, 1981); however, needed social support may not always be adequately available from other family members, the care recipient, or the community in general (Grant, 1996). Community programs exist to support informal caregivers both physically and mentally, such as support groups, educational resources, and training courses (Marziali & Donahue 2006). Barriers to accessing these services such as logistical,

geographical and time constraints often make it difficult for caregivers to benefit fully from these programs (Anderson et al., 2010; Stewart et al., 2002; Wright, Lund, Pett & Caserta, 1987).

Often, care will not be provided by an individual caregiver but by a network of caregivers known as secondary caregivers (Wolff & Kasper, 2006). In addition, care networks may include caregivers who are involved in care even if they do not live in the same area as the care receiver, known as long-distance caregiving (Bevan & Sparks, 2010). These care networks complicate caregiving as they add a dimension of necessary care coordination. Care may be provided by formal services alongside informal services, which adds an additional aspect of care involvement. Although caregivers wish to foster relationships with service providers, these relationships sometimes do not occur (Gantert, McWilliam, Ward-Griffin & Allen, 2009).

Recently, online networks have shown the potential to enrich social support and interactions for caregivers by overstepping common barriers to accessing community-based support, such as availability barriers (e.g., for rural-dwelling caregivers), financial barriers and scheduling barriers, and internal barriers such as psychological and physical conditions while fostering a sense of community among participants (Czaja & Rubert, 2002; Marziali & Donahue., 2006; Robinson, Patrick, Eng & Gustafson, 1998 as cited in Schulz, Lustig, Handler & Martire, 2002; Setoyama, Yamazaki & Nakayama, 2011; Zloty, Roger & Lobchuk, 2011). Along with helping to address barriers associated with accessing community support resources, online support services are also able to address caregiver information and social support needs (Czaja & Rubert, 2002; Schulz et al., 2002; Zloty et al., 2011). Setoyama and colleagues (2011) have identified five benefits offered to support group participants that are common to both face-to-face support groups and online support groups: emotional support, emotional expression, advice, insight/universality, and conflict (a negative aspect of social support). Examples of such online communities include PatientsLikeMe (www.patientslikeme.com) and AlzOnline (<http://alzonline.php.ufl.edu>) (Glueckauf & Loomis, 2003). Resources for Enhancing Alzheimer's Caregivers Health (REACH) is an example of a caregiver network that was received positively by end-users. REACH operated through telecommunications designed to support caregivers

caring for the same patient by enabling better communication and information access, and gained positive user feedback (Czaja & Rubert, 2002). Similar web-based technologies include Lotsa Helping Hands (<http://www.lotsahelpinghands.com>) and Tyze (<http://www.tyze.com>), which have been created to allow multiple caregivers known to one another to coordinate care for a single care recipient (Lotsa Helping Hands, 2012; Tyze, 2012). Tyze, a Canadian-based service, may be a tool that can enhance informal-formal relationships and social support available to informal caregivers.

Tyze Personal Networks is an online tool that allows members in a network of care to collaborate and coordinate care. Tyze networks are centred primarily on the care recipient; encompassing the notion of 'patient centred care'. Tyze currently has 7000 users averaging around 7 people per network, and works closely with over 50 organizations in Canada, the United States, and the United Kingdom (Cammack & Byrne, 2012). Tyze connects caregivers electronically; however, service providers are a component of face-to-face care networks missing from these online networks. Tyze offers features such as a calendar for scheduling, claiming tasks, posting notes, and sending messages. Tyze also offers a private area for posting sensitive information, called the vault, which may only be accessed by designated network members.

The involvement of service providers in online and face-to-face networks would be significant because service providers provide informal caregivers with information, procedural knowledge, care support, and knowledge about how to navigate the health care system (MaloneBeach, Zarit & Spore, 1992). These contributions are especially important because informal caregivers often feel unprepared for their role and that they do not have the necessary skills or training to perform caregiving tasks (Given, Sherwood & Given, 2008). Research supports the desire of informal caregivers to feel supported by service providers as partners in care (Gantert et al., 2009; MaloneBeach et al., 1992). Specifically, caregivers want to be seen as care partners who have the opportunity to provide considerable input for decision-making, while feeling better prepared to take on caregiving tasks. Caregivers report that barriers to forming relationships with service providers include time and contextual barriers (Gantert et al., 2009).

Online networks have the potential to serve as invaluable resources for facilitating caregiver-provider relationships: It is known that patients and caregivers wish to form relationships with providers; however, these relationships are often challenging to build (Gantert et al., 2009). Online networks have the potential to provide a convenient way for all to stay actively involved in a patient's care. Online caregiver networks could provide a point-of-contact with a service provider and serve to address continuity of care issues that our health care system currently faces. For care to be continuous, information sharing and communication must be consistent and seamless between service providers and with informal caregivers (Haggerty et al., 2003). The inclusion of service providers in patient online personal networks such as Tyze could act to improve patient satisfaction with care, and address common caregiver issues such as anxiety, social isolation and geographic barriers. This study will investigate the perceptions of service providers, case managers, and informal caregivers on the potential to use an online network to facilitate informal-formal continuity of care.

CHAPTER 2: LITERATURE REVIEW

2.1 Overview of Population Aging in Canada

The Canadian population is aging primarily as a result of greater life expectancies and lower birth rates (United Nations Department of Economic and Social Affairs, 2002; Statistics Canada, 2008). Between 1981 and 2005, the population of adults over the age of 65 has doubled (Statistics Canada, 2006). This trend will continue, and, by 2030 it is estimated that at least 20% of the population, or 10.4 million people living in Canada, will be over the age of 65 years (Human Resources and Skills Management Canada, 2011). This trend is partially a result of the baby boomers (that is, those born between 1946 and 1964 during a period of high birth rates) reaching older adulthood (Statistics Canada, 2006; 2008). The segment of the population aged 65 years or older is growing most rapidly, and within this demographic, those over the age of 85 years are the fastest growing (Public Health Agency of Canada, 2009).

Coupled with the continued aging of Canada's population is a resultant increase in the prevalence of age-related chronic diseases (Public Health Agency of Canada, 2011). These conditions take many years to develop so it is not surprising that they are most common in older adults (Fries, 1980). While chronic disease is not inevitable in late life, over 77% of non-institutionalized adults over the age of 65 have been diagnosed with at least one chronic disease (Gilmour & Park, 2006), and 33% of older adults are living with three or more chronic diseases (Gilmour & Park, 2006). Chronic diseases are responsible for over 80% of cases of disability in later life (Upton, 1977 as cited in Fries, 1980). Disability due to chronic diseases persists for an average of 6.5 years in women and 3.4 years in men before death (Hebert, 2002). Although disability may be manageable in early stages of progression, over time individuals may need to turn to family members or formal services for additional care (Gilmour & Park, 2006).

The rising interest in accessing services in the home has fueled a shift away from institutional care (long-term care homes). This trend has been supported by Ontario government initiatives, which recently, have invested \$700 million dollars into aging at home strategies that support services available

for community-dwelling older adults (Ontario Ministry of Health and Long-Term Care, 2002). Aging at home allows older adults to maintain independence (Canadian Research Network for Care in the Community, 2011; MOHLTC, 2002) that may not be possible in a long-term care facility (Williams et al., 2010). The issue is that for many frail older adults, living at home may not be realistic without the assistance of an informal caregiver (Williams et al., 2010).

Home care services are available to assist some individuals with activities of daily living (ADL), instrumental activities of daily living (IADL), emotional support and health system navigation (CIHI, 2010; CRNCC, 2011; Levine Reinhardt, Feinberg, Albert & Hart., 2004;). ADL activities may include bathing, toileting, grooming, dressing, mobility, and eating, while IADLs include meal preparation, cleaning, housework, laundry, medication management, house maintenance, transportation, shopping, banking and bill paying (Baumgarten et al., 1992; Hollander, Liu & Chappell, 2009). When frail older adults require assistance with activities of daily living, they may turn to home care services provided most often by personal support workers (PSWs) or unpaid family/friend/neighbor caregivers.

2.2 Caregiving in Canada

Paid home care services are available for frail older adults living at home, however, informal care is the primary source of care for older adults. In fact, only 8% of individuals rely exclusively on formal caregiving, while 14% receive care from both formal and informal caregivers, leaving 78% of this population who rely on informal care alone (Health Policy Institute of Georgetown University, 2004).

The majority of informal care received by older adults in Canada is provided by the care recipient's family members: Specifically, 75 % of married care recipients are cared for by their spouse, while 75% of unmarried care recipients are cared for by their children (CIHI, 2010). Caregivers tend to be female relatives caring for a husband or parent (Zukewich, 2003) who have entered their role as a caregiver due to perceived family responsibility, or by choice alone (Health Canada, 2002).

There are over three million informal caregivers in Canada providing care to 2.3 million older adults (Cranswick & Dosman, 2008). On average, caregivers ages 45-64 years and 65 years or older provide 7.9 and 10.4 hours of care per week, respectively (Hollander et al., 2009). However, certain conditions may require a much greater time commitment than is reflected by the reported averages. For example, dementia patients often require 24-hour live-in care and surveillance (Andersson, Levin & Emtinger, 2002; Grunfeld, Glossop, McDowell & Danbrook, 1997). The contribution to care by informal caregivers is equivalent to over 275,000 full-time workers (Fast & Keating, 2001) valued at approximately 25 billion dollars in 2009 (Hollander et al., 2009). Accordingly, Wolff & Kasper (2006) describe informal caregivers as “the backbone of the long-term care workforce”.

2.2.1 Costs of Caregiving

Providing care may become a challenge for caregivers when their own needs and full-time employment, and other family commitments must be balanced with caregiving roles (Lee, Walker & Shoup, 2001), and as a result, caregivers often find themselves unable to address their own personal needs, their employer demands, or the needs of the care recipient (Anderson et al., 2010; Clemmer, Ward-Griffin & Forbes, 2009; Gordon, Pruchno, Wilson-Genderson, Murphy & Rose, 2012; Ho, Collins, Davis & Doty, 2005). Although there are many positive aspects of caregiving, such as giving the caregiver a sense of being needed or valued as well as contributing to the family (Cohen et al., 2002; Boerner et al., 2004; Tarlow et al., 2004), caregiving also has many associated personal costs (Baumgarten et al., 1992; Butterworth et al., 2010).

Caregiving is associated with physical, social, emotional, spiritual and economic consequences (Townsend, Ishler, Shapiro, Pitorak & Matthews, 2010), including: increased stress; anxiety; depression; anger; frustration; physical illness; financial stress; social isolation; lower reported life satisfaction; and employment disruption such as missed work and lost productivity (Aggar et al., 2010; Baumgarten et al. 1992; Burton et al, 2004; Butterworth et al 2010; Clemmer, et al., 2009; Fast et al., 2002; Ho et al., 2005; Lee et al., 2001(a)). Negative personal consequences associated with caregiving

are sometimes referred to as caregiver distress or burden, while the inability to balance work and caregiving roles is referred to as role strain. The burden endured by informal caregivers creates additional consequences for employers and care recipients. Employers must compensate for sick days, lost productivity and wages, and other work limitations, while care recipients may not be receiving adequate care or may face institutionalization in part as a result of caregiver burden (Burton et al., 2004; Gordon et al., 2012; Ho et al., 2005). Studies that explore ways to address caregiver burden have determined that social support is important in mitigating the personal costs associated with caring for frail older adults. In fact, the importance of social support has been widely emphasized for informal caregivers facing stresses associated with their role as a caregiver (Butterworth et al., 2010; Pearlin, Mullan, Semple & Skaff, 1990)

2.2.2 Social Support and Implications for Informal Caregivers

The implications of social support for caregiver health have led researchers to determine which aspects of social support networks specifically contribute to positive caregiver outcomes. Research has suggested that social support network size is not an important factor in caregiver burden, and that instead; both perceived social support and satisfaction with available social support are associated with more positive care outcomes (Schaefer et al., 1981). The reason for these findings is that a vast social support network will not be beneficial to an individual who does not perceive that they are receiving support from their network (Schaefer et al., 1981). Perceived social support and satisfaction with social support have both been shown to have a positive impact on caregiver health and studies show that formal support and familial support play different roles in moderating caregiver burden (Fudge et al., 2007; Sandler & Barrera, 1984). For example, caregivers primarily receive information from formal support sources and are provided with emotional support from family and friends (Jung, 1984).

Caregivers benefit from having strong social networks as they contribute to a protective effect against the negative consequences of caregiving. Benefits of strong social support to caregivers may include: the sharing of information, focusing on healthier lifestyles (Bloom, 1990) (caregivers tend to

neglect their own health when caring for someone else (Connell, 1994)), providing emotional support, promoting well-being (House 1981 as cited in Fudge, Neufeld & Harrison 1997), improving self-efficacy, coping abilities, quality of life (Northouse, 2010), and increasing life satisfaction (Haley, Levine, Brown & Bartolucci 1987). Similar findings have been shown in palliative care research (Clemmer et al., 2009).

In light of these findings, many interventions have been developed with the purpose of providing support to caregivers. Pearlin and colleagues (1990) maintain that insufficient social support is a contributor to caregiver burden. Pearlin's model also points to prominent available social support and proper coping as mediators to negative health outcomes associated with caregiving. Caregiver support interventions should therefore enable coping and provide social support (Pearlin et al., 1990).

2.2.3 Interventions to Improve Social Support Available to Informal Caregivers

The value of social support to caregiver well-being and life satisfaction has received considerable recognition (Grant, Elliott, Geiger & Bartolucci, 2001), leading to numerous interventions aimed at strengthening social support for primary caregivers. Caregiver support services include community support groups, in-home support, and respite care (Marziali & Donahue 2006). Often, caregivers are unable to benefit from these services because of insufficient time for attendance, transportation barriers preventing attendance, highly dependent care receivers who cannot be left alone, or financial issues rendering them unable to afford these services (Anderson et al., 2010; Stewart et al., 2002; Wright et al., 1987). Montgomery & Kosloski (2009) advise that social support interventions for caregivers be adaptable to the role diversity of caregivers and must recognize the dynamic role of providing care. In addition, these support interventions need to be convenient in terms of time and location (Stewart et al. 2002).

2.2.4 Caregiving Networks: Secondary and Long-Distance Caregivers

When an older adult requires assistance from an informal caregiver, it is not uncommon for other family members or friends to become involved in care as well (Fast, Keating, Otfinowski &

Derksen, 2004). Keating and colleagues (2003) note that it is often inadequate to describe models of care as an interaction between the caregiver and the care recipient, and that often caregiving involves a care network.

Primary informal caregivers are not always the sole caregiver of an older adult; in 47.2 percent of cases, secondary caregivers may also be involved in providing care (Wolff & Kasper, 2006). Secondary caregivers are defined as those who provide care alongside a primary caregiver, though usually not as intensely or as often (Tennstedt, McKinlay & Sullivan, 1989). Caregiving tasks for secondary caregivers tend to be periodic activities such as shopping, transportation, and home repair (Tennstedt, McKinlay & Sullivan, 1989). Those primary caregivers receiving additional help from either formal or informal sources are more likely to be caring for an older adult relative with more severe disability than those who are receiving care from a single caregiver, and as a result, the primary caregiver themselves will often require greater support (Wolff & Kasper, 2006).

Caregiving from a distance (generally measured as living more than a one hour drive away) is common and has implications for communication and emotional support between caregivers (Bevan & Sparks, 2010; Rosenblatt & Van Steenberg, 2003, Statistics Canada, 2007). In Canada, 22% of informal caregivers live more than an hour drive away from their family member receiving care (Statistics Canada, 2007). Although these caregivers are living further away from their family members, they tend to travel to remain involved with the care recipient regularly and as a result, require more information, take more time off work and have more financial costs than more proximal caregivers (Statistics Canada, 2007).

Long-distance caregivers tend to contribute through compiling information for care and arranging services rather than providing direct care (Rosenblatt & Van Steenberg, 2003). These tasks are challenging for long-distance caregivers, and research demonstrate that distance caregivers face the same stresses as proximal caregivers, though certain aspects such as finance and work stressors may be more pronounced (Statistics Canada, 2007).

Requisites for successful long-distance caregiving include organizing caregiving roles with other informal caregivers; remaining in contact with the care recipient's other informal caregivers and service providers in order to remain well-informed about care; and creating a care plan with other involved informal caregivers (Lewis, 2008).

2.2.5 Care Partnerships: Formal-Informal Collaboration and Support

According to Statistics Canada (2006), 42% of adults aged 85 years or older report using home care services, while 8% report receiving informal care accompanied by formal care (Health Policy Institute of Georgetown University, 2004). Older adults receiving a combination of formal and informal services tend to be suffering more complex health issues than those who exclusively rely on one source of care (Statistics Canada, 2006).

In light of research findings highlighting the benefits associated with strong provider-caregiver relationships such as increased competence and confidence in care, better decision-making and decreased burden (McWilliam et al., 1999 ; Ward-Griffin & McKeever, 2000), care strategies have begun to shift towards a focus on facilitating therapeutic relationships between clients, caregivers, and service providers (Registered Nurse Association of Ontario, 2006), also known as the nursing triad (Dalton, 2005). Evidence suggests that the quality of a caregiver relationship with a service provider contributes to caregiver burden if inadequate, and conversely, a well-developed relationship can contribute to positive health outcomes for caregivers (Francis, Worthington, Kypriotakis & Rose 2010). In addition to benefitting informal caregivers in terms of their ability to provide care, service providers are able to provide informal caregivers with education and social support to which they might not otherwise have access (Ward-Griffin & McKeever, 2000). This relationship is not one-sided; service providers benefit from relating with informal caregivers because informal caregivers provide information on the client that is important for care, and contribute to caregiving tasks even while service providers are present (Sims-Gould & Martin-Matthews, 2010; Ward-Griffin & McKeever,

2000). Informal caregivers can provide service providers with additional patient information and care updates that further contribute to continuity of care.

Informal caregivers often express interest in forming relationships with their service providers, however, these relationships are not always fostered in the way informal caregivers hope in terms of the quality or dynamics of the relationships (Wiles, 2003; Ward-Griffin & McKeever, 2000). Relationship forming between formal and informal care providers face several challenges including contextual barriers, time constraints, and role negotiation (Gantert et al., 2009; Ward-Griffin & Marshall, 2003). In terms of contextual and time barriers, informal caregivers providing care to a highly-dependent relative who is unable to be left alone may feel compelled to use the time the service provider is present as an opportunity for completing errands outside of the home (Gantert et al., 2009). Informal caregivers may also be unable to develop a relationship with formal care providers if there is a lack of continuity of care because of inconsistent formal care provider presence (Gantert et al., 2009; Haggerty et al., 2003). Additionally, role boundaries may be unclear for informal caregivers in terms of creating care plans and delegating care tasks, often leading to power-struggles between informal caregivers and service providers (Ward-Griffin & Marshall, 2003). Other research has suggested that a barrier to forming these partnerships is a lack of information sharing or simply, that families are not interested in becoming involved with service providers (Laitinen & Isola, 1996). Strategies that may facilitate positive care partnerships should be time efficient while encouraging communication and fostering a sense of partnership and continuity of care (Gantert et al., 2009).

2.2.6 Continuity of Care

Continuity of care refers to consistency in care delivered to patients over the entire course of their care (Haggerty et al., 2003). Haggerty and colleagues (2003) have identified three types of continuity: informational continuity, management continuity, and relational continuity. Informational continuity relates to information about a client's preferences, values, context, and medical condition; informational continuity contributes to care by ensuring care provided is appropriate to each unique

client. Management continuity ensures that procedures for managing a condition are “responsive to a patient’s changing needs” (Haggerty et al., 2003, p. 1220). Finally, relational continuity is about the relationship between client and provider. These are an important aspect of care because they influence the quality and coherence of care delivered to clients and caregivers (Haggerty et al., 2003). Continuity of care, and specifically, management continuity, becomes especially crucial during care transitions where the consequences of fragmented care are amplified (Reid, Haggerty & McKendry, 2002).

Continuity of care has important implications from the point of view of caregivers, clients, and providers (Haggerty et al., 2003). To clients and caregivers, continuity of care implies that clients will be following a consistent care plan with a familiar provider with whom they have formed a relationship; for providers, this means that necessary information is complete and available when required (Haggerty et al., 2003). Both aspects point to the importance of well-established formal and informal relationships. A study examining the aspects of care continuity that are perceived as being important by home care clients (Woodward, Abelson, Tedford & Hutchison, 2004) suggested that clients want care that is seamless, active, and easily maintained.

2.3 Technology for Caregivers

Worldwide, the internet has over two billion users (International Telecommunications Union, 2010), with Canadians being the heaviest users in terms of time spent online (Akkard, 2011; Comscore, 2011). The implications of widespread internet use in Canada are vast for health care delivery. A poll by Harris Interactive (2010) found that 88% of adults who report using the internet have used it to access information related to their health. Specifically, through the internet, online communities exist to provide information and support for connecting patients with common diseases, such as PatientsLikeMe (www.patientslikeme.com), and caregivers of patients with common disease, such as AlzOnline, an online resource on Alzheimer’s disease (<http://alzonline.php.ufl.edu>).

2.3.1 Social Support Online

Online communities are defined by Whittaker and colleagues (1997) (as cited in Preece & Maloney-Krichmar, 2003) as members using an online resource (e.g., a forum) who are seeking and sharing related information, providing and receiving support and are connected by common goals, interests, or needs (e.g., managing Alzheimer's disease, coping with depression, hobby-related); 84% of internet users have been part of an online community at some point (Horrigan, 2001). Online social support communities for informal caregivers have shown promising outcomes with proven reductions in caregiver stress, depression, and increasing confidence in caregiving ability and perceived support (Bass, McClendon, Brennan & McCarthy 1998; Torp, Hanson, Hauge, Ulstein & Magnusson., 2008). More generally, online communities have documented benefits to community members by meeting user needs such as information sharing and exchange, problem-solving, and social support (Johnson & Ambrose, 2006). Online community members also report that these communities have helped them improve their self-care, understanding of a medical condition, and decision-making ability (Fox & Raine, 2000).

A report released by the National Alliance for Caregiving (NAC, 2011) explored the potential for informal caregivers to use various types of technology to assist them in caregiving. The technologies explored included medication management tools, personal health record tracking, and caregiver coordination systems. Of the caregivers involved in the study, 63% of caregivers in general, and 70% of long-distance caregivers said they would be likely or somewhat likely to use a caregiver coordination system (NAC, 2011). A separate portion of the study revealed that 70% said they perceived this service as useful if it was obtained, paid for, and set up for them (NAC, 2011). In general, informal caregivers felt that different types of caregiving technology would save time, make caregiving easier, reduce stress and depression, save money, and increase the connectedness and independence of care recipient (NAC, 2011). This report also investigated the perceived barriers to using technology in caregiving. The most common perceived barriers to the use of a caregiver coordination system included cost (31%), the perception that the service would not address a need

(17%), and care recipients' resistance to change (15%) (NAC, 2011). Other perceived barriers included the perception that this would decrease user privacy, would be too time-consuming to learn to use, and would take away from social interactions (NAC, 2011). Informal caregivers said they would be more likely to use the service if they had a service provider explain how the service was helpful, were given advice regarding setup, had the service recommended from an online forum, or had the service approved by their agency (NAC, 2011).

Computer illiteracy can be a barrier to these services; however, this issue has been addressed in previous research. It has been suggested that the use of online caregiver resources require little training or computer literacy if they are well-designed (Bass et al., 1998; Brennan et al., 1991; Brennan et al., 1992; Czaja & Rubert, 2002; Hill & Weinert, 2004; Owens & Robbins, 1996; Torp et al., 2008). Brennan and colleagues (1992) and Owens & Robbins (1996) each found that regardless of educational background; less than two hours of training was required before participants in each study were able to use their respective caregiver services properly. Additionally, the former study found that the service was most heavily used at times when community resources are not likely to be available. Again, this speaks to the appropriateness and advantages of online resources for informal caregivers.

2.3.2 Tyze Online Network

A potential solution that might help to bridge the gap between informal caregivers and service provider interaction and as an indirect result, address issues in continuity of care and inadequate social support is the Tyze online network. Specifically, Tyze is an online networking tool that is designed to improve patient care through networking informal caregivers together while providing social support and avoiding potential travel or time constraints.

Tyze networks centres on a care client and connects caregivers that are providing care to a common client. Currently, Tyze has 7000 users in Canada, the United States, and Europe (Tyze, 2012). Services that Tyze provides include private and group messaging, photograph sharing, document sharing, goal setting, task assignment and appointment planning. Tyze ensures privacy by limiting who

may access each document in the network (such as medication and appointment information (Tyze, 2010). Tyze may have the potential to further contribute to care quality if the integration of service providers into these networks is seen as acceptable by providers and caregivers. The purpose of this would be to foster care partnerships between informal caregivers and service providers while providing additional support to informal caregivers. In addition to the benefits to clients and caregivers, the inclusion of service providers has the potential to help address issues surrounding inconsistencies in providers and treatment plans that hinder continuity of care. Finally, home care clients are often admitted to home care following a hospitalization, so this service has the potential to address transitional care issues often seen in these patients relating to poor communication between formal and informal caregivers.

To date, little research has been conducted on whether the inclusion of service providers in such online forums is feasible, let alone whether clients, informal caregivers, and service providers are interested in using this type of service together to bridge gaps in care and facilitate formal-informal partnerships.

CHAPTER 3: STUDY RATIONALE

As the population continues to age, more Canadians become informal family caregivers to close friends and family members. Despite the benefits associated with caring for a loved one, it has been well-established that caregiving is a stressful role that often leaves individuals vulnerable to their own health issues such as depression, anxiety and sleep disturbances (Aggar et al., 2010; Baumgarten et al., 1992; Butterworth et al., 2010; Lee et al, 2001(a)) However, research does support the role of social support in buffering the impact of these stressors on health outcomes (Pearlin et al., 1990; Schaefer et al., 1981). While support is available through community programs, online social support resources may be beneficial to achieving person-centred care through informational, relational, and management continuity through better information-sharing and communication facilitation (Anderson et al., 2010; Haggerty et al., 2003; Marziali & Donahue, 2006; Stewart et al., 2002; Wright et al., 1987). Research has shown that primary caregivers often are part of a larger care network involving other family members serving as secondary informal caregivers, and a variety of health care providers (Wolff & Kasper, 2006). As care may be provided to a single home care client by many formal and informal caregivers; communication between involved parties is essential to caregiving.

Informal caregivers are usually interested in forming relationships with service providers in order to be able to provide better care (Gantert et al., 2009; Ward-Griffin & McKeever, 2000). Interacting with service providers is important for informal caregivers because formal services are an invaluable source of information and social support (Given et al., 2008), and they provide informal caregivers with the skills they need to provide optimal care to the care recipient in terms of decision-making, noticing and understanding health changes, monitoring symptoms, and navigating care (Schumaker et al., 2000). Research has also demonstrated that informal caregivers, health care providers, and clients each play an important role in the caregiving process. Specifically, informal-formal relationships help ensure that caregivers, who sometimes perform tasks they are not trained nor qualified to complete, are better prepared for their (sudden or possibly unexpected) transition into the caregiving role and do not have unanswered questions (Given et al., 2008), especially when this information is available to caregivers early in their care trajectory(Toscan, 2011). Health care providers

and secondary informal caregivers have unique and important roles in terms of the kinds of social support they are able to provide to primary caregivers. However, due to a lack of time, interest and issues surrounding continuity of care, formal-informal relationships are not always created successfully.

Rogers (1995) has developed the “*Theory of Diffusion of Innovation*” that describes how components of an innovation and the innovation’s intended users’ influence whether or not uptake will occur. Rogers’ theory also describes stages of uptake (Figure 1). These stages are knowledge, persuasion, decision, implementation, and confirmation. Research exploring the intended users’ perceptions of technology should be conducted during the knowledge stage; that is, when end-users who have been exposed are still in the early stages of understanding the technology. This thesis study will therefore begin in the knowledge stage because this is an early stage, appropriate for gauging intended users’ perceptions of an innovation before money is invested in the diffusion of innovation within an organization. However, participants will move into the persuasion stage as they are asked to consider whether they would use online networks in home care. According to Rogers’ theory, there are three kinds of knowledge that may exist within the knowledge stage: awareness, how-to, and principles knowledge. When encouraging innovation adoption, research efforts may be focused on proliferation of both awareness and how-to knowledge (Rogers, 1995).

In order for an innovation to be successful in terms of adoption, it must meet five characteristics as perceived by the target audience: relative advantage (how does this innovation compare to the existing solution?) complexity (is the innovation difficult to figure out?) trialability (can this innovation be tested in a short-term period before committing to its use?); observability (are the benefits from innovation use obvious); and compatibility (does the innovation match the users’ values/needs/workflow?) (Rogers, 1995). Research suggests that service providers tend to be in the late majority for technology adoption (Johnson & Ambrose, 2006). Frantz (2001) has suggested that if a new technology is to be used in home care, Rogers’ theory of diffusion of innovations is a useful tool for assessing whether the technology will be successful. When researching a new innovation, research should take place in the knowledge stage of uptake and should focus on proliferating awareness and

how-to knowledge. This means allowing potential users to become aware that the technology exists, how it is used, and what purpose it serves.

3.1 Purpose and Objectives

As a networking tool, Tyze has the potential to address the needs of informal caregivers and service providers who are providing care for frail older adults within the home by addressing their need for social support and continuity of care. Informal caregivers have expressed interest in using technology to assist with caregiving (NAC, 2011). Although Tyze currently provides online networks between informal caregivers, the next step to facilitating the care networks is to involve service providers, who are an important component of caregiving. Through the inclusion of service providers and informal caregivers, care partnerships could be facilitated leading to a more integrated care network. This study will focus on service providers (who, as of yet, are scarcely involved in online networks) but will also include informal caregivers and case managers.

The objectives and research questions of this study are as follows:

- 1) To explore whether informal caregivers and service providers perceive the inclusion of health care providers in an online network as a useful and/or positive addition to the care they provide;
 - a. Do informal caregivers and service providers see themselves using an online network in home care? Why or why not? Who could they see using online networks?
- 2) To investigate whether online networks are perceived as having the potential to address ongoing continuity of care issues that are encountered by clients and caregivers; and
- 3) To identify facilitators that will enable this intervention to be successful in future trials; along with barriers that must be considered and/or addressed in order to create a successful intervention.
 - a. What are the barriers to the success/adoption of an online network in home care?
 - b. Can these barriers be addressed, and if so, how?

CHAPTER 4: STUDY METHODS

4.1 Epistemology

In qualitative research, the chosen paradigm reflects the researcher's basic belief systems according to his or her epistemological and methodological assumptions (Guba & Lincoln, 1994). The researcher must define his or her position as this impacts the chosen methodology and methods, as well as the nature of the researcher-participant relationship, and framing of findings (Carter & Little, 2007). For this study, I have chosen an objectivist paradigm. The objectivist paradigm demands that the researcher remains separate from his or her research in order to find an objective reality through the research questions (Guba & Lincoln, 1994). According to objectivism, the researcher is trying to approximate reality, but acknowledges that this is never completely possible. Although it is not possible to be entirely separate from the research, for this topic it was appropriate that the researcher remains as objective as possible to discover the current reality of stakeholder perceptions (Guba & Lincoln, 1994). This research study is intended to be descriptive in order to develop an understanding of the perceptions of participants to an online network based on their views of technology and healthcare as it fits in with their own lives (Sandelowski, 2010).

4.2 Declaration of Self

My interest in this topic developed gradually. I first became interested in gerontology during the second year of my undergraduate studies when I enrolled in an introductory gerontology course. To me, this course was fascinating and from this point forward I was certain that I would pursue a gerontology degree in some capacity. Research that focuses on caregivers and older adult care recipients has become a specific interest of mine because I feel that the difficulties encountered by these people as they attempt to navigate the healthcare system can be readily addressed with the cooperation of various stakeholders. During my academic career I have come to recognize that health care issues such as these need to be addressed at multiple levels – societal, policy, community, individual levels, for example, and must target varying levels of need. In short, one intervention is not enough for everyone, but if it can help address a “pocket” of need then it is a useful intervention.

Prior to my Master's, most of my experience had been in quantitative research through various research methods and statistics courses I had taken throughout my undergraduate degree. I shifted towards qualitative research during my graduate career because I felt that the questions I wanted to ask about the potential for Tyze would not be possible in the depth I was hoping for if I used quantitative methods. Specifically, I wanted to examine attitudes and perceptions in-depth, and felt that the kinds of questions I could ask in order to elicit strictly quantitative data would not provide me with the level of understanding I was hoping for. I wanted there to be a dialogue with informal caregivers and home care staff; as well I wanted to be able to ask "Why?" to any type of response I received.

4.3 Methodological Approach

This study follows a generic qualitative approach (Avis, 2003; Caelli, Ray & Mill, 2003; Sandelowski, 2000). Tension exists between qualitative experts on the nature of generic qualitative research. Sandelowski (2000; 2010) argues that while generic qualitative research may involve no interpretation of the findings, good qualitative research cannot forego interpretation. In order to create a separation between generic qualitative research and the research she defines as qualitative description, Sandelowski (2000) makes suggestions on how to create a structured qualitative study (and later advises that her naming of qualitative description brings to light conflicts that arise when distinguishing between nuances in terminology). Therefore, this study will use a generic qualitative approach while remaining mindful of the importance of interpreting the data rather than simply repeating it. This methodology has been chosen because it was well-suited to the objectives of this research; that is, to explore perceptions, feasibility, and barriers and facilitators to the implementation of technology to facilitate communication between family members and home care staff (Carter & Little, 2007; Sandelowski, 2010). Other methodologies include grounded theory, phenomenology, ethnography, and participatory action. Although generic qualitative research is becoming increasingly common, researchers often feel compelled to "force" their research into one of the more widely accepted methodologies such as grounded theory or phenomenology, when their actual methodology does not

quite fit with any of these (Sandelowski, 2000). Generic qualitative research does not follow a strict philosophical position; therefore, it becomes especially crucial that the researcher must clearly detail the study methods, the researcher's reflexivity and how rigour was achieved (Caelli et al., 2003; Cooper & Endacott, 2010). The researcher must also describe his or her theoretical positioning (see sections 4.1 & 4.2); the strategies used to establish rigor; and the analytic lens used to approach the data (Caelli et al., 2003).

4.4 Focus Group as Chosen Technique/Method

Focus groups bring together a small group of participants (typically four to twelve) (Kitzinger, 1995; Krueger & Casey, 2000) from specific populations (Wilkinson, 1998). They rely on the communications and interactions that occur between participants to generate data, primarily through explaining perceptions, asking questions, discussing disagreements or agreements, and telling personal anecdotes (Kitzinger, 1994, 1995; Wilkinson, 1998). A benefit of focus group interviews is that they are able to observe interactions between group members can be observed as they explore a particular topic. Through the interview, participants clarify their opinions and priorities, and are able to express themselves in their own language (Kitzinger, 1995). In addition, focus groups are advantageous for exploring the success potential of a new innovation, and therefore have been chosen as the primary method for this study (Krueger & Casey, 2000).

Focus groups can separate participants based on their role in order to prevent social desirability bias and to allow for open discussion (Krueger & Casey, 2000), as was done in this study. Specifically, participants were separated into focus groups based on their role in home care (e.g., case manager, home care staff, informal caregiver). Oftentimes, participants may be unwilling to express themselves candidly if they feel this will compromise their relationship with other participants or with those who hold different roles and status within groups. Additionally, this design allowed for the researcher to identify discrepancies and commonalities between different roles in home care (Onwuegbuzie, 2009).

All focus group interviews used the same interview guide with wording modifications that reflect role and group differences (e.g., "...your role as a case manager", "your role as a caregiver").

4.5 Study Rigour and Trustworthiness

A common criticism of qualitative research (generally by those who prefer a positivist approach) is that it is strongly biased by the researcher and does not produce generalizable findings (Mays & Pope, 1995). In order to ensure rigour and trustworthiness of data, there are steps that can be taken by the researcher throughout the research process (Mays & Pope, 1995). Techniques were chosen in order to address issues around reliability and validity that are relevant to the chosen research methodology. This section will outline the techniques that were used to meet each of the three validity criteria recommended: credibility, reflexivity, and transparency.

4.5.1 Credibility

Qualitative research findings are considered authentic and credible if they represent the participants and subsequent data accurately, including differences that may arise between participants and participant groups (Hammersly, 1992 *in* Whittemore et al., 2001; Whittemore et al., 2001). This study used three techniques in order to address authenticity and credibility of findings: Triangulation of participants, member checking, and dissemination of findings.

Triangulation is used by researchers in order to gain a complex understanding of a research topic from the different perspectives of those involved in the issue of interest (using Tyze portals), and to ultimately increase study credibility (Farmer, Robinson, Elliott & Eyles, 2006). Investigator triangulation, data triangulation, methodological triangulation and theoretical triangulation are cited as common types of triangulation commonly used in research (Denzin, 1978 *in* Farmer et al., 2006). In this study, the perceptions of three participant groups were investigated: CCAC case managers, home care staff, and informal caregivers.

Member checks use a consultative process with study participants in order to confirm that study findings reflect the viewpoints of participants and to establish credibility. These sessions may generate

new information or lead to the modification of current findings (Hoffart, 1991). This study used a member check session through email to ensure that the findings reflected those of the study participants. Each study participant was emailed the study findings and asked if they had additional inclusions or general comments pertaining to the findings.

Dissemination of Findings -The findings from this study will be shared with interested home care agencies, personnel at Tyze, as well as the Waterloo Wellington Community Care Access Centre, with the intention of enhancing study authenticity and generating discussion amongst those who are able to implement such services. This allows the organizations to determine how findings may be used in a meaningful way to enhance or inform the service they provide.

4.5.2 Reflexivity

Addressing reflexivity in this study is important for qualitative research in order to add to the depth of the findings. Reflexivity demands that the research can both acknowledge and express his or her subjective influence on the research process (Patton, 2002). This study addresses the need for reflexivity using the following three techniques.

Declaration of Self - This technique allows the researcher to describe his or her worldview and to quantify what has drawn the researcher to the specific research topic and methodological approach. This provides the researcher with an opportunity to become aware of any personal biases towards the research topic.

Reflexive Journal - Morrow (2005) advises that keeping a reflexive journal is an excellent practice in maintaining researcher reflexivity. The researcher uses the reflexive journal to “keep an ongoing record of his or her experiences, reactions, and emerging awareness of any assumptions or biases that come to the fore” (Morrow, 2005). The researcher kept a reflexive journal throughout the research process. This journal included any thoughts about the research process or findings that the researcher found to be particularly interesting, important, or poignant. The following is an excerpt from the researcher’s reflexive journal:

Re: not trusting technology: Participants (all groups) want to know that information posted online will be confidential and information won't get into the wrong hands. I would be interested in finding a way to determine how people make decisions about which technologies they feel they can trust. For example, people seem to trust email in their personal lives, but in a workplace environment (and specifically for health information) it seems to be a big problem. In my experience trying to recruit participants, I found that the CCAC would not email me participant contact information for informal caregivers but they were willing to fax it to me in our office. This struck me as odd because anyone could have accessed the document if it was sent during a time where I wasn't at work to obtain the document. In the end, they gave me a sheet of paper with everyone's names and numbers when I was at their office in person. This could have been arguably more easily lost (and found by a stranger) than anything sitting in my email inbox.

Peer Debriefing - involves consulting with colleagues about the study direction and methods. The researcher engaged in frequent informal and formal peer debriefs by discussing the research with colleagues and committee members on a regular basis. From these debriefing conversations, the researcher gained insight into her own subjectivity, opposing interpretations of the research, and further interpretation of the research findings ("I hadn't thought of it that way!") through the expertise and varying experiences of colleagues (Morrow, 2005).

4.5.3 Transparency

Transparency in qualitative research is important because the methodologies tend to be less structured than quantitative research approaches. Transparency demands that the researcher is clear about every step taken during the study. Transparency has been obtained in this study by providing

specific details about the recruitment and data collection processes. For example, this paper has provided the number of participants present in each focus group interview and the number of participants who did not consent to audio-recording as well as the impact this may have had on study findings. By creating a reflexivity journal and audit trail, the researcher has maintained transparency in the research process.

An *Audit Trail* was kept on my personal computer in a Word document and updated when required, in the form of memos. The purpose of the audit trail was to document the steps I took during data analysis and any thoughts and considerations I encountered during the data collection phase in order to establish authenticity in my research (Guba & Lincoln, 1989 in Cutcliffe & McKenna, 1999). The audit trail includes a collection of notes taken during meetings with committee members and discussions with colleagues relevant to this research and consisted of key points from the discussion. These notes were later inputted into a Word document. The audit trail somewhat resembles a log of events relating to the project. In addition to contributing to study transparency, the audit trail speaks to the reflexivity of the researcher. The following is an excerpt from the audit trail.

Date	Research & Analysis Decision Log	Who was involved
November 1, 2011	Meeting with Paul re: study parameters <ul style="list-style-type: none"> • Still including ICG • Be consistent in using terms like aim, purpose, goal • Remove sub-objectives from proposal, they aren't helpful in this case • CCAC ethics – contact Brent by Nov 4 • Use same inclusion criteria as [home care agency 1] 	EP, PS

	<ul style="list-style-type: none"> • Give a piece of paper to participants for comments at end of session 	
November 1, 2011	Kerry sent [home care agency 1] research proposal for reference	KB
November 3, 2011	Kerry and Justine spoke about my involvement with the [agency 1] study. The focus group (phone) has been moved to December 6 th with a group from Windsor.	KB, JT
November 4, 2011	Kerry has sent feedback on my proposal but feels it will be useful to discuss further over the phone on November 7.	EP, KB

4.6 Recruitment Overview

Purposive sampling (Patton, 2002) was used for this study, meaning, participants were selected strategically to best answer the research questions (Mays & Pope, 1995). In particular, criterion sampling was used, by selecting participants who are in some way involved in the provision of formal or informal care, as case managers, home care staff (dietitians, physiotherapists, occupational therapists, nurses, personal support workers), or informal caregivers. Home care clients were not used because this study is focused on exploring the perspectives of informal and service providers on a potential strategy to improve care coordination. In addition, online networks are already used by informal caregivers and clients. This study is aimed at exploring the potential for including paid caregivers (home care staff) in online networks.

In total, 36 individuals participated in this study. These participants were spread across five focus groups (groups ranged from two to nine participants), one face-to-face interview and three

individual telephone interviews. Each interview lasted no longer than one hour (each ranging from 40-60 minutes). Interviews were audio-recorded (with consent of participants) using audio-recording equipment loaned from the School of Public Health and Health Systems at the University of Waterloo. All but one focus group interview was audio-recorded (due to one or more participant(s) who did not consent to being audio-recorded). During the interview that was not audio-recorded, both the researcher and the research assistant who were present took notes by-hand describing the interview responses in point-form. All interviews followed a semi-structured interview guide and the researcher probed participants to elaborate when appropriate (Krueger & Casey, 2000). Each interview had at minimum one research assistant from InfoRehab (www.inforehab.uwaterloo.ca), a research program dedicated to enhancing care through better health information usage, present to manually record nonverbal cues such as facial expressions (Krueger & Casey, 2000). Recruitment and interviews took place between April and July of 2012. Following each interview, the researcher and research assistant would debrief regarding key points of the focus group interview, comments that should be further explored, overall impression of the focus group interview (Krueger & Casey, 2000). The researcher and research assistant also wrote about the focus group in terms of content and technical issues.

Audio recordings from the interviews were transcribed verbatim into an unabridged electronic text document (Krueger & Casey, 2000). The resulting data were compiled with notes taken by the research assistant into a file and were uploaded into NVIVO8 for analysis. See Data Analysis section for details on this process.

Theoretical Saturation - Data saturation and subsequently participant saturation occurs when it becomes evident no new themes or ideas emerged from the interviews (Glaser & Strauss, 1967). Although new codes may be uncovered in any given number of interviews and saturation is never truly reached, a certain point in the research process will occur when the number of new codes generated by each interview is minimal (Guest, Bunce & Jonhson, 2006). For this reason, it is important that data analysis occurs concurrently with data collection as was done with this study. For this study, saturation was reached only for service providers (see limitations).

Limitations in Recruitment- This study presented several recruitment limitations. The study period coincided during the time that the WWCCAC had encountered a resource constraint. As such, they were limited to providing one focus group interview session of six participants during the six-month period of this study. These same resource constraints led to limitations in recruiting informal caregivers. Due to time constraints and participant shortages, participants who may have not met initial inclusion criteria (e.g., computer literacy as a requirement) were not excluded from study. Home care providers were unable to recruit informal caregivers due to cited confidentiality reasons; therefore, all informal caregivers were recruited through the WWCCAC.

4.7 Community Care Access Centre (CCAC) Case Managers

Waterloo-Wellington CCAC (WWCCAC) case managers were invited to participate in a focus group interview. CCACs are funded and regulated by the Ontario Ministry of Health and Long-Term Care, and there are 14 regional CCACs in Ontario in total. The role of the CCAC is to connect people who are accessing the health care system with home care and long-term care, and community services using case managers, who generally are Registered Nurses (CCAC, 2012). Although case managers do not deliver direct care in the home, it is important that they are in agreement with the use of an online network because the CCAC plays a big role in whether or not service providers may become involved in the networks.

A designated location contact at the WWCCAC was first contacted with a study overview. The location contact agreed to provide WWCCAC home care staff with an information letter and consent form (Appendix A). Interested WWCCAC staff agreed on a time when they were adequately available to participate in the focus group interview and the interview session was scheduled.

To be eligible for participation, WWCCAC staff were required to meet the following inclusion criteria:

1. Must be computer literate; and, 2. Must be available during the study period. WWCCAC staff who met the following criteria were excluded from study: 1. Non-English speaking; and, 2. Insufficient computer literacy (determined based on ability to use email).

4.7.1 Data Collection

An extended focus group design was used. This approach requires that a brief questionnaire be administered to participants prior to having them answer focus group interview questions. Benefits of the extended focus group designs include encouraging participants to commit to a particular standpoint even if this standpoint places them in the minority (Wimmer and Dominick 1997). The questionnaire used for this study asked participants questions about their day-to-day technology use and if they viewed online networks positively.

One focus group interview was held with WWCCAC case managers. This interview was facilitated by a University of Waterloo researcher (EP), and an additional note-taker (RA from the University of Waterloo).

The focus group interview began with an introduction of the study, acquisition of written consent to participate and presentation of the information letter and confidentiality agreement (Appendix A). Participants were asked to complete a demographics survey (Appendix B) that would later be used to describe the study sample. Next, a questionnaire requiring approximately five minutes to complete was administered that explores general perceptions of health technology using a likert-scale (Appendix C). Following completion of the questionnaire, participants were shown a five-minute demonstration video of Tyze.

After the demonstration, research questions were addressed through the focus group interviews (Appendix D). The study finished with a post-interview questionnaire requiring no longer than five minutes to complete (Appendix E). This questionnaire was used to measure if and how participant perceptions had changed following the video demonstration focus group interview. Pre- and post-questionnaires were kept anonymous through coding with an identification number. At the end of each questionnaire, participants were provided with blank space to write any additional comments about Tyze and the study in general. Although the researcher intended on audiotaping the proceedings of this focus group interview, full consent to interview was not obtained, and the researcher and the research

assistant took notes by hand instead. WWCCAC case managers did not require participant remuneration.

4.8 Informal Caregivers

Informal caregivers were recruited for this study as they play an integral role in home care. Often, informal caregivers wish to act as partners in care, contributing to the care decision-making process. The importance of caregiver-provider partnerships has been emphasized in the literature. The contribution of informal caregivers to this study was important for thoroughness in exploring perceptions of end-users of online networks.

This study followed a recruitment method that the InfoRehab research team had previously found to be successful (ORE #16435) for recruiting informal caregivers through the WWCCAC. This process involved a two phase consent process:

WWCCAC case managers were asked to identify informal caregivers eligible for the study and contacted them via telephone/in-person to provide information regarding the study (Appendix F for telephone script), along with the opportunity to provide written/verbal consent to be contacted by a University of Waterloo researcher. Once consent was obtained, information regarding the caregiver's contact information was provided to the University of Waterloo researchers. Next, the researcher contacted interested caregivers via telephone to provide them with more detailed information about the study, request verbal consent to participate, and determine the caregiver's preferred method of contact/participation (face-to-face, focus group interview or phone-interview). The informal caregivers were also asked to provide an email address to which the Tyze preview video, along with additional study information (Appendix G) and a sample of the interview questions (Appendix H) could be sent and to schedule the interview.

In order to be eligible for participation, caregivers were required to meet the following criteria:

1. must identify as the "primary caregiver" (defined as an informal caregiver who spends the most time assisting or caring for the care recipient (e.g., preparing meals, dispensing medication, and providing

transportation) for a home care client; and 2. must have access to a computer and the internet. In addition, participants were excluded from study if they fit any of the following criteria: 1.non-English speaking; 2.insufficient computer literacy; 3.does not have access to a computer with audio; and, 4.currently involved in another caregiver intervention study.

In total, four informal caregivers were recruited for study.

4.8.1 Data Collection

Participants who identified themselves as informal caregivers were unable to meet collectively to participate in a focus group interview. Instead, informal caregiver interviews were conducted face-to-face onsite at the WWCCAC headquarters and over the phone (n= 1 face-to-face interview and 3 individual phone interviews). Interviews began with consent (either written or verbal), followed by the completion of a demographics questionnaire (Appendix I). Next, participants were asked to view the Tyze demonstration and subsequently respond to a series of interview questions based on the Tyze portal. Informal caregivers who participated in phone interviews were first called by the researcher to confirm their interest in the study, and to get their email information in order to be sent subsequent documents. Next, the researcher sent the interview guide, engagement letter, and Tyze demonstration video via email, and asked that the participants view these prior to the scheduled phone call.

Participants who were interviewed over the phone were asked to view the video demonstration prior to participating in the phone interview. Participants were then called and answered interview questions. Pre- and post- demonstration questionnaires were not administered to informal caregiver participants as the primary purpose of these questionnaires was to encourage participants to commit to a particular standpoint during focus group interviews in particular.

Informal caregivers were sent a \$25 gift card redeemable at Chapters for their participation.

4.9 Home Care Service Providers

Three separate organizations participated in focus group interview sessions. For interviews with Home Care Agency 1, staff were be recruited by researchers involved in a separate study from Home

Care Agency 1 and Tyze. The participants from the remaining home care agencies were recruited through location contacts at each respective organization. Staff members who expressed interest in study participation were provided with an information letter and consent form from the location contact (Appendix J for agency 1; Appendix K for agency 2, 3). Letter and consent forms were different for agency 1 due to their ethics guidelines. Location contacts were responsible for final recruitment and focus group scheduling.

4.9.1 Home Care Agency 1 Focus Groups

The Home Care Agency 1 focus group interview sessions (n=2) differed slightly from the other sessions because they did not follow an extended focus group design and they were not asked questions about care transitions. This was because this Agency was unable to gain clearance for the extended focus group questionnaires due to time constraints. Home Care Agency 1 focus group interviews were run by the researcher and moderated by a Home Care Agency 1 staff member who works closely with Tyze and was able to answer participant questions related to the portal in detail. Home Care Agency 1 did not require study remuneration.

4.9.2 Home Care Agency 2 and 3 Focus Groups

Focus group interviews conducted with Home Care Agency 2 (one group) and Home Care Agency 3 (two groups) followed the same focus group procedure as was used with WWCCAC Case Managers (Appendix B, D, C, E).

Home Care Agency 3 staff received remuneration in the form of \$75.00 cash for participation as required by the organization. Home Care Agency 2 staff received remuneration in the form of lunch provided during the focus group sessions.

4.10 Ethics, Participant Confidentiality, Benefits, and Risks

This project received clearance from the Office of Research Ethics at the University of Waterloo (ORE#17694). Although focus group participants may know the identity of other participants,

they were asked to maintain the confidentiality of all participants. Collected data will be stored for five years and only researchers directly involved with this study will have access to data. Electronic data were password protected while paper documents were stored in a secure area on-campus at the University of Waterloo. All data have been de-identified to protect anonymity. Five years after the completion of the study, all data will be destroyed.

There were no anticipated benefits or risks to research participants. Although this was not encountered, participants were allowed to withdraw from study at any time and were not required to answer questions that they were not comfortable answering.

4.11 Data Analysis

Analysis occurred concurrently with data collection (Krueger & Casey, 2000); the justification for simultaneous analysis is that it improves the data collection process by allowing researchers to identify which research questions require more information to answer so subsequent interviews can address these potential information gaps (Krueger & Casey, 2000).

The study followed an inductive approach. Different approaches impact the type of coding used in the study as well as the research findings (Braun & Clarke, 2006). An inductive approach was chosen because the researcher did not confine analysis to pre-existing codes, but rather, worked with the data in order to generate codes (Braun & Clarke, 2006). Although this study did not adhere to pre-determined categories defined by existing research, the researcher had become familiar with existing literature, or sensitizing topics, relevant to the research topic which was used to guide analysis. For example, the researcher became familiar with theories of innovation adoption (Rogers, 1995), continuity of care (Haggerty et al., 2003), and network theories (Sims-Gould & Martin-Matthews, 2010). A full exploration of sensitizing topics can be found in the study introduction.

This study followed a generic qualitative approach. Qualitative research requires the researcher to be extremely familiar with the data to be analyzed. To achieve data immersion, the researcher read each transcript four times without coding (Braun & Clarke, 2006, Crabtree & Miller, 1999 *in* Bradley,

Curry & Devers, 2007). Next, the researcher listened to audio-recordings of interviews in order to fill in gaps left by transcribers and to become familiar with the group dynamics of each interview (Braun & Clarke, 2006). During these tasks, the researcher wrote memos describing her thoughts about the transcripts, and where she could see connections being made between ideas, phrases, and codes (Morse & Richards, 2002).

Descriptive Coding- The first step in this analysis was descriptive coding. This involves recording factual information about the data, such as context and setting of the interviews or information on the participants (Morse & Richards, 2002). The purpose of descriptive coding is to be able to see connections between participant characteristics and interview responses, if they exist (Morse & Richards, 2002). For this study, participant information was collected using a demographic questionnaire, where information was later inputted into a table. Information about interview locations and context were recorded in post-interview memos written by both the researcher and her research assistants.

Topic Coding - NVivo8 was used during topic coding. Topic coding was the next step used by the researcher during analysis. The purpose of topic coding is to group data together based on topic, so that all the data on discussion matter can be easily retrieved and further sorted, but also to give the researcher an overview of the reoccurring topics from the data (Morse & Richards, 2002). The codes were data-driven and during the initial coding phase, were descriptive (Morse & Richards, 2002). Data were coded based on the topic being discussed in the interview transcript.

Analytic Coding - As more categories emerge, coding enters the analytic coding phase. During this part of analysis, codes are sorted into categories (Morse & Richards, 2002). Morse & Richards (2002) describe this phase as “taking off from the data”, because the researcher is now doing more than simply labeling parts of the transcript. The researcher makes connections between codes and places these in categories (Morse & Richards, 2002).

Theme-ing - Finally, theme-ing occurs throughout all stages of analysis (Morse & Richards, 2002). The researcher identified themes as pieces of the data that were threaded throughout the interviews. The categories were sorted into themes and subthemes by the researcher.

Finally, the interviews were re-read in order to ensure that the hierarchy of themes accurately represented the data, and any pertinent themes, categories, or codes that had been lost during analysis were considered.

The member check was conducted using email or mail. Participants who expressed interest in being involved in the member check, by agreeing for a follow-up in the consent form, were emailed or mailed a summary of study findings and asked to provide any feedback based on the results.

Feedback from the member check was sparse with only four respondents. All respondents agreed with the findings and only one participant had additional feedback. Feedback was related to a more detailed point of the study findings that were included in the results but not in the member check letter due to the specificity of the findings. The following is an excerpt of study feedback from the member check session.

``Thanks for the information. I think you have captured the feelings at the focus group very well. I have nothing further to add. I hope the project will go forward for a further study, as there definitely is a need for this type of service.

Good luck``

CHAPTER 5: RESULTS

5.1 Summary of Participants

In total, this study included 35 participants, consisting of 31 service providers and four informal caregivers spread throughout four individual interviews and six focus group interviews. Focus group interviews took place at each agency's headquarters. Three interviews took place over the phone with informal caregivers. Interviews were conducted between April and July 2012. Participants were recruited from three home care agencies, and one CCAC. Service provider groups were based out of Toronto, London, Hamilton, and Kitchener-Waterloo, all cities in Ontario. Informal caregivers were all residents of Kitchener-Waterloo. For more detailed information about participants, see Table 1 and 2 for service providers and informal caregivers respectively.

5.2 Summary of Questionnaires

The pre- and post-demonstration findings suggested that participants were generally accepting of technology and their perceptions were not swayed by the focus groups. The exception to this trend was with CCAC case managers, who were more open-minded to technology prior to the focus groups, but afterwards, rated identical questions about the usefulness of technology in home care with "uncertain". This may have occurred as a result of a strong voice in the focus group interview, or perhaps due to uncertainty specific to the network that was shown in the video demonstration.

Table 1: Summary of Service Provider Participants

Group (n)	Gender	Age	Years in Role	Position	Highest Level of Education
1(5)	5 F, 0M	19-24 (2) 45-54 (1) 55-64(2)	1-5 (2) 6-10(1) >10(2)	Personal Support Worker (3) Nursing Manager Nursing Supervisor	Some college (1); Completed college (3); University undergraduate (1)
2(5)	5 F, 0M	25-34(1) 35-44(3) 55-64(1)	<1(1) 1-5(2) >10(2)	Regional Therapy Services Manager (2) Quality Manager + Social Work Lead Occupational Therapist Physiotherapist	Completed college (1) Some post-graduate (1) Post-graduate (3)
3(7/8)	7 F, 0M	25-34(3) 35-44(1) 45-54(3)	<1(1) 1-5(4) >10(2)	Speech Language Pathologist (3) Occupational Therapist Service Coordinator Professional Practice Lead (2)	University undergraduate degree (4) Post-graduate degree (3)
4(2)	2 F, 0M	45-54(2)	<1(1) 1-5(1)	Manager of Quality and Education Client Care Manager	Completed college (2)
5(5)	5 F, 0 M	25-34(1) 45-54(2) 55-64(2)	1-5(2) 6-10(3)	Registered Dietitian Occupational Therapist(2) Social Worker Professional Practice Lead	Some University (1) University Undergraduate (2) Post-graduate (2)
6(4/6)	4 F, 0 M	45-54(4)	1-5(1) 6-10(1) >10(2)	Case Manager (4)	Completed College (1) Some University (1) University Undergraduate (2)
Total (28/31) 3= Prefer not to answer	28F	19-24 (2) 25-34(5) 35-44(3) 45-54 (13) 55-64(5)	<1(3) 1-5(12) 6-10(5) >10(8)		Some college (1) Completed College (7) Some University (2) University Undergraduate (9) Some Post-grad (1) Post-grad (8)

Table 2: Summary of Informal Caregiver Participants

ID #	Age	Sex (M/ F)	Education	Employment	Care Recipient; Care Recipient Age	Conditions (n)	Living with Care Recipient?	Primary Caregiver? Since?	Hrs/We ek from ICG	Who do you ask for help
1	58	F	College	Full-time	Spouse; 59	3+	Y	Y; 10+ years	Full- time	None
2	67	M	University	Retired	Spouse; 64	1	Y	Y; <1 year	Full- time	Family member
3	78	F	Post- graduate	Retired	Spouse; 81	3+	Y	Y; 1-5 Years	Full- time	Family member
4	58	F	High- school	Full-time	Mother; 85	3	N	Y; 1 year	Full- time	Neighbour

5.2 Study Findings

Table 3: Summary of Themes

Theme	Subtheme
Current State of Affairs	Room for Improvement
Making the Rules and Setting Boundaries	One Size Does not Fit All
	Knowing the Rules Before You Play
	Resistance and Barriers to Use
	What's in it for Me?
	Testing the Water Before We Jump in
Navigation and Integration	Coordinating Care Through Better Communication
	Focusing on the Client Through Better Information-Sharing
	Supporting Informal Caregivers
	Supporting Transitions

Data analysis resulted in three themes: 1. The Current State of Affairs; 2. Making the Rules and Setting Boundaries; 3. Navigation and Integration. These themes each describe different aspects about the perceptions of online network use based on the analysis of the study interviews. The Current State of Affairs describes how study participants spoke of their current methods of communication and technology use, including shortcomings of these methods. Making the Rules and Setting Boundaries describes the circumstances, questions and concerns of network use expressed by participants. Navigation and Integration explores the perceived benefits of network use, specifically in relation to improving aspects of communication and information sharing. These themes were created by combining data from three data sources: service providers from a variety of backgrounds, CCAC case managers, and informal caregivers.

5.2 The Current State of Affairs

Current State of Affairs describes current aspects of home care that participants felt are working well, along with those that are not working well. This theme shows an opportunity for improvements to be made in home care delivery.

Participants explained that service providers and informal caregivers communicate with one another, either face-to-face, or through leaving notes, telephoning, or emailing. Participants gave mixed responses as to whether each form of communication was effective. Not all participants (informal caregivers and service providers) were dissatisfied with their current available method of contacting other providers and clients. Generally, these were participants who found it easy to contact their health care providers or clients over the phone, and felt that current methods of communication were working well. There was evidence to suggest that satisfaction and dissatisfaction with communication, information, and support resources in home care were associated in some way with the complexity of the client and family situation. Specifically, informal caregivers who had less complicated care predicaments had fewer difficulties coordinating care with service providers. In addition, they tended to be part of smaller care networks (See: Making the Rules and Setting Boundaries).

Face-to-face conversations between service providers and informal caregivers are not always considered appropriate if the client is within earshot. These conversations may take place in the form of a phone call once the service provider has left the client's home. The content of such conversations may include discussion about a client's [declining] health or behaviours. For example, a service provider explained that some clients with dementia may become agitated if they hear service providers talking about them over the phone:

Service Provider 1: ...There is the time that we will call from our phones if it's something huge or from the client's phone depending on the client and if they're going to get upset or not.

Service Provider 2: Yeah. Like we have one client, if they don't eat dinner, we have to call the family. So have the number and either call from the house phone, which is usually what they request, but with this client in particular, they may get very upset about you calling the family member all the time. So sometimes you have to do it from your cell phone or something.

(Agency 3, group 1)

Leaving notes in the home is a method of communication often used by service providers and informal caregivers to communicate with one another. Notes can be lost, misunderstood or thrown out and the intended recipient may not receive the information from the note. The use of notes to deliver information between caregivers requires that the caregiver is in the home of the client to receive these notes. This is a problem for service providers who do not make frequent home visits, and for informal caregivers who do not live with the care recipient. There is no guarantee that notes are being found or received. Sometimes, family members or health care providers may forget to leave notes for each other. This becomes a concern when information is not consistently communicated as health care providers coming into the home may be unsure of how to proceed. As described by one participant, this may place formal and informal caregivers in a position where they make assumptions about care:

Service Provider: It's like with our one client, it'd be good to know, like she, now she writes us a note but it'd be good to know when the meds are filled because it has caused problems before where people don't know when they're getting filled. And then people don't know if she's had her meds or not. And that's a problem. (Agency 3, group 2)

Families who are not entering the home constantly to read notes often end up calling the home care agency. This creates more work for the agency. Notes are not always appropriate for communicating about client care and face-to-face or phone conversations may be more appropriate, but these methods also have shortcomings.

Participants felt that they often do not have time for an entire telephone conversation. Informal caregivers who said they preferred using email because their work schedule makes them difficult to reach were told by their service providers that they were not allowed to communicate through email (see: Boundaries set by governing bodies).

Linda: They're not allowed to [email us]. Then there are phone calls, and good luck on catching me. When they're working I'm working. I don't own a cellphone. I work in a factory. I can't be running to the phone. My other job, I ran the office so it didn't matter. It worked well; she called me all the time...I'm in the plant now and I'm not getting a cellphone. I can't afford it.
(Informal caregiver)

Health care providers interviewed described heavy caseloads while informal caregivers involved in this study felt that their caregiving role was a full-time job on top of their other commitments.

Service Provider: I think too, there is probably lots of seniors again I'm thinking of those seniors who might not all be active participants and maybe family then but um lots of caregivers are at that point in life where they are very busy and sitting down and making phone calls and talking for lengthy periods of time over the phone with their family members isn't possible yet to be able to be on the internet and quickly add information and say hello or give them an update or send a picture they might be able to do that for the senior. (Agency 1, group 1)

Although service providers are willing to speak over the phone, because of the nature of their job they do not have an office number at which they can easily be reached. Instead, they use their personal cell phones. Service providers interviewed said they were not comfortable sharing their personal contact information with their clients, which makes using cell phones an issue unless their agency has provided them with work phones. Providers do not want to be called from clients during

their time off, and felt that by providing their personal phone numbers to clients, this would be inevitable. To avoid giving out personal contact information, service providers said that they ask families to call the agency office and have their calls forwarded to their service provider. One participant described how phone conversations currently take place with clients.

Service Provider: Not everyone can block their numbers on their phone and a lot of people these days have caller ID, and then also you can call on your phone, “oh, my mother is changing this time” and it's like, “well you've got to call the office” and then you have like four families calling you, kind of thing. So [online networks] kind of would help eliminate that. Because then we don't have to risk our phone numbers being given out. (Agency 3, group 1)

Online networks were seen as a way to eliminate extra calls to the agency office as well as a way to eliminate multiple phone calls to the service providers throughout the day that can become difficult to manage. Overall, this theme suggests that the individuals involved in this study saw an opportunity for their current communication in home care delivery to be improved. They were receptive to online networks as a potential solution, if not for themselves, then for others. The next theme explores the steps that must be taken before online networks can be used in home care to facilitate communication.

5.3 Making the Rules and Setting Boundaries

Participants wanted to be clear on the boundaries of use for online service use in order to have an understanding of how this type of service would work. This theme developed into four categories: a. One size does not fit all; b. Knowing the rules before you play; c. Resistance to use (barriers); and d. What's in it for Me?

5.3.1 One Size Does not Fit All

Participants described the circumstances in which they felt the use of an online network would be both appropriate and beneficial. The situations described in these instances were related to managing complexity in chronic care. Participants agreed that online networks would be useful for cases involving clients who have dementia, who are palliative, or who have a developmental disability. Online networks were deemed appropriate for these clients because of the complexity associated with these conditions.

Service Provider: It's like, I have someone, a palliative client, who's got tons of people coming in all the time, and the wife suffers from a lot of on the edge burnout because, it's just coming and going all the time, and she feels like she needs to sort of keep things organized, but this would really help put the onus on a lot of other people. (Agency 1, group 2)

The ideal populations for online network use to support caregivers are clients who are unable to care for themselves or who require care for a longer time period. Complex clients often have many individuals coming into the home – both service providers and informal caregivers.

Doug: If you're doing something on your own it's a big job and you'll definitely need help, and for those people type of people they would be using your [online network] left right and centre, wanting more and more help and guidance. (Informal caregiver)

Participants suggested that online networks would be helpful for informal caregivers and service providers of clients who have multiple caregivers or appointments to juggle.

Service Provider: I wonder if another population would be, maybe not a person with dementia themselves, but a caregiver for a person with dementia, you know, if you're even as a family, you know, bringing over meals, I'll take Monday, Wednesday, Friday, um, because the other feature of it, are that there are pictures associated with each name. Um, so sometimes the visual really helps. You know, they say oh, all these people are coming and going, I don't

know who's who, but it puts a picture to a name, um, so it's easier to keep straight, who's who.
(Agency 1, group 2)

Participants associated complex clients with long-term home care use, which was where online networks were described as being potentially helpful. Participants did not think that low-complexity clients and their informal caregivers would benefit from the use of online networks.

Service provider: I think it's got to be sort of a complex client. Like, a person who is elderly and, you know, handling their diseases and everything pretty well, I don't think they need to be doing something like this. It sounds to me like this is more for people that have a lot of problems that the family wants to keep on top of because someone like your dad, it wouldn't be any use setting this up for him because he can handle his own. (Agency 3, group 1)

Participants explained that they did not think that short-stay clients who recover quickly would need to use online networks to help them manage their care. Study participants explained that it would not be helpful to offer an online network service to informal caregivers who were the lone caregiver providing care, as this network was seen primarily for complex situations with a variety of caregivers.

Marge: If you had a lot of people. It's not like...for me I am the only one really. (Informal caregiver)

Informal caregivers who were not involved in "sharing the care" felt that an online service would be of no benefit to them. Online networks were frequently described as being potentially helpful in keeping long-distance caregivers engaged and up-to-date in care.

Service Provider: I could see it for caregivers that live at a distance, that want to stay connected. Like we have lots of family members that may live out west or you know, in the States, or whatever, and they want to hear from us, "What are you doing and how often are you going? What do you recommend?", and that's a lot of phone calls, or getting answering

machines or, for them to try and call us, we're out of the office a lot, so good luck trying to reach us. So, I mean if there was a way of posting, "We recommend this piece of equipment", and then they confirm that they accepted it, they're taking care of it, then we have confirmation that our recommendations are being followed through. So I can see when we can't meet face to face with people, they live at a distance. That could help with them staying in touch with the client, but also, us, getting our messages to them, and having responses. (Agency 1, group 2)

This would allow informal caregivers who may not be able to meet personally with the home care staff to remain involved in care, as this service provider has described.

Finally, although online networks are set-up to facilitate care for a client, participants did not feel that it would be mandatory for the client themselves to be on the network. This would be in cases where the client is unable to become involved in their own care but has many other people involved in care. Participants indicated that there were many cases where they could see a network being set without involving the client themselves. They suggested this type of situation would be with clients who do not have the cognitive or physical capacity to access or become involved with the network, again, feeding into the concept of managing complexity in care .

In order for service providers and case managers to agree to use online networks with their clients, they expressed that it would not be realistic or appropriate to become involved with networks for their entire caseload. Case managers suggested that they could see the online network being useful for 20% of their caseload. Along with aspects of home care that were perceived to fit well with the demonstrated features of online networks, participants outlined where they felt these networks would not be suitable. Specifically, participants did not see online networks being appropriate for delivering urgent messages, for those who have issues with computer usage, or for those who did not feel the need for social support. Posting urgent messages that require attention immediately is inappropriate,

according to study participants. Rather, it would be acceptable to post updates on routine tasks completed in the home.

Service provider: ...But you still have to call them though, because something like [client not eating dinner] shouldn't wait until you get it into a computer and the family, and that family member decides to go check that website. That's the sort of thing you do have to notify right away...But there are some things, like even the garbage you're saying. Well, I don't want to have to call the client every single time, "Oh, well I didn't take the garbage out" – like last night I didn't take the garbage out of a client's house because it was really windy. I knew the garbage came – in the process, they're going to get blown away and that garbage is going to end up everywhere. So I kept it till this morning. (Agency 3, group 1)

There are potential liabilities as a result of using online networks to enhance home care. Health care providers were concerned that they would be liable for not checking the network if informal caregivers posted urgent messages that the providers did not receive in time. Participants indicated that urgent messages should be delivered by phone.

When asked if online networks could play a role in facilitating hospital-to-home transitions, participants commented that it was unlikely that there would be the time for the hospital to set up a network during the client's stay. If the network existed prior to the transition, participants agreed that it would be beneficial for enabling better access to client information.

Service provider: We would never get...there is never enough time, discharges are so fast.
(Agency 3, group 2)

Participants thought that information about any hospitalizations that may arise could be added to the network, but they did not think it would be realistic for the service to actually be set up during the transition.

Participants felt that online networks would be inappropriate for those who do not wish to communicate using a computer. Issues with computer usage may be related to lack of computer literacy or dislike of using computers. Online services are not something that everyone may be comfortable with, and participants indicated that these services would be better suited for those who are comfortable with technology. When participants described this aspect of a potential user for online networks, they often associated this trait with an informal caregiver or client who was younger.

Service Provider: As [service provider] pointed out, there's going to be a certain demographic that's going to not even use this because they're just not computer savvy and who probably feel a little intimidated by the website but that would – but like you say, the family, younger family members would be able to use it. (Agency 3, group 1)

Computer literacy was frequently cited as a potential constraint to online network use for both family members and clients. Clients and informal caregivers who wish to be involved in the network may require training, but there was concern that training may not be enough for those who have very little experience using a computer.

Many participants stated that they may simply not enjoy using the computer and do not view time spent on the computer as a hobby or pass-time. Those who did not view computer usage as a pass-time felt like this may present as a chore rather than as an activity they would enjoy.

Service Provider: ... And there's some people that are, it's not so much a comfort level, it's like ...to sit there, she can't understand. "What are they doing sitting there all the time?" Right? [Laughter] She can't understand that. Get up off your butt and you know, sweep the floor instead. (Agency 2, group 1)

This sentiment was shared by an informal caregiver, who stated:

Mary: I hated the computer in my job...I worked at [place of employment]...And you know the computer was a big part of my job and so I had to have one at home, you know, I really had to have one. But now that I am busy with [my husband] and his care, sometimes I don't get on it but once a week. I don't pass time on it, you know, it is something that I need to do or need to send an email. You know, it is a necessary thing rather than a pleasure sort of thing. (Informal caregiver)

Finally, the social nature of online networks would serve no use to informal caregivers who do not wish to share caregiving-related information with their network.

Mary: I am not a social person. Never have been. I was never into kaffeeklatsches and things like that. I have always been a very um, laid back person and um, I feel like if someone needs the communication with other people, I think it would be wonderful. (Informal caregiver)

Participants agreed that there is a definite time and place for the use of online networks in home care, and this is likely with informal caregivers who enjoy connecting electronically and who are caring for a complex, long-term client.

5.3.2 Knowing the Rules Before You Play

This subtheme is about the parameters of use. Before becoming involved, service providers and informal caregivers want to know “What exactly am I getting myself into?” By making the rules before implementation, end-users are able to make better informed decisions about their willingness to use the online network for home care. Specifically, participants wanted to know how costs would be covered, who would control the network, who is involved and to what extent, and how long the networks would last.

Online networks may have associated financial costs. For the network to exist, participants were interested in knowing how costs would be covered and for how long. Participants were concerned that this would be a barrier to use for families who could not afford network costs. Interview participants agreed that it would be helpful if the agency offered the online service to their clients as part of the service they provide. This concept refers to aspects of the duration of the online network, ranging from where the service should be introduced to clients and families, and how long it should be available for them to access. This was an important item to be considered, especially if costs were to be subsidized by a home care agency. Participants agreed that it would be useful to allow families and clients to access the online network upon their entry into the system, but if it had not been introduced immediately, it could be helpful at any point during the client and family's care journey.

Service provider 1: Most people are either going to die or get better if they're still with us. Like once we're done with them.

Service provider 2: Unless it's like, for example, about, you know, a complex school health client who could be on service for 10, 15 years.

Service provider 1: Right. And then [our agency] would keep supporting them, right? (Agency 1, group 2)

If the network was subsidized by the home care agency, participants agreed that it would be acceptable to offer this service until their relationship with the agency ends. They felt that this would be an appropriate amount of time to offer the service because generally, when a client no longer receives home care services, it is because they have recovered or because they have passed away or have transitioned into long-term care. Prior to using online networks, participants were eager to discuss rules and expectations of use.

Participants were interested in determining many aspects of network access, such as who may access, post, view the network, and how much information access would be involved for different members. These questions were voiced by service providers and case managers, who have more

experience with care networks of different sizes and relations, whereas informal caregivers were only considering how online networks would benefit their own network, therefore were less concerned with these types of boundaries. Participants discussed how extensive online networks would be. They debated the potential for involvement from community members, such as meals-on-wheels volunteers who worked with the client. Participants agreed that it would be helpful to have the entire care-team involved; however, network involvement could quickly become excessive. Informal caregivers may have conflicting ideas of the best way to provide care for the client and participants said that this would create an outlet for those conflicts. The existence of a network would also provide an opportunity for network members to have input in the client's care, but participants were concerned that this input could potentially become excessive.

Service Provider: Sometimes that's just when there's, cause you hear that all the time, you go into a client's home, you're doing an assessment, you've got two daughters there, a son, well, they want this, they want that, they want this...there's going to be all of that on there, so sometimes, it's like, what's the best for the client, may not always be what the family members want. (Agency 2, group 1)

Another participant debated that these conflicts are nothing new; however, online networks would bring these issues to the forefront. Health care providers expressed discomfort with posting information about the client on a network that could be accessed by anyone on the network, including family friends, who may not necessarily be heavily involved in caregiving.

Service Provider: I guess I would just be concerned about the kind of information that is shared depending on what you are there to provide the clients. Is someone that is driving the client would want to share some information but if the therapist is going in they might want to share, you know, other types of information that might not be appropriate for the driver to have of the client so I don't think there is "the wall" but... (Agency 3, group 2)

It was suggested that this may lead to issues surrounding confidentiality. If the network had widespread involvement, there would need to be different levels of information access for different network members. Participants did acknowledge that this feature was provided by the vault, which is a place where only certain network members using online networks may access. However, they suggested there may need to be multiple levels of different access to information, rather than the two-tiered system of access offered by the vault.

Ownership issues in relation to the online network were frequently discussed by service providers and case managers. Participants discussed concepts such as who owns the network and the information posted on the network. Discussion over who should control consent for the network to exist (client vs. informal caregiver) and over who has access to the network became a concern in the case where the family members want to use an online network, but the client does not consent to it. Participants described several concepts for how this could be resolved. First, a waiver and consent form would need to be provided to families and clients (if they too are cognitively able to give consent) outlining the terms of use for the online network. In this way, families and providers could reach an agreement on the extent of information that would be acceptable to post online. Next, participants (case managers and service providers) were unsure whether there would need to be client consent for the network's existence, regardless of whether the client accessed the network themselves. If the client did not want the online network to exist, this could be a barrier to network start-up if health care providers are legally required to gain consent from clients prior to network involvement. This piece of the network puzzle has implications for who has the final say over network contents, including who may have access. Discussion turned to deciding how provider-client relationships would play into network involvement. A scenario that was explored by participants was if the client chose which service providers were allowed network access. Participants wanted to know how to resolve an issue such as if the client were to invite all of their service providers onto the network except for one that they did not like.

Service Provider: Um, I was wondering, you were saying that only the grandmother, for example, that one example, only the grandmother would be the administrator, so she would have the sole ability to invite who she would want or not want. So for example, if the grandmother liked the occupational therapist, but didn't like the physiotherapist she might invite one person but not another? (Agency 1, group 2)

Whether or not a network was still being actively used, participants were interested to know how long the information posted onto their network would be stored or accessible. These conversations between participants indicated a separation in regulations regarding information physically kept by the agency, and information posted online. Service provider participants indicated that agencies were required to store information for ten years. Participants voiced concerns about the permanence of information posted to the internet. Participants were not confident that any information stored online is ever completely deleted.

Service Provider 1: I just thought of another thing , so should information...how long should it stay up there, I mean for example with Facebook, everything is up there since you opened your network or your account so should this have a finite amount of time that something is up there...

Service Provider 2: Well as far as our information goes, we would be obliged if we were discharging them to download it and put it in their file because we have to keep a health record or what would be considered health information, it has to be kept for ten years. (Agency 3, group 2)

During the focus groups, these questions often led to discussions about information ownership. One participant noted that different provinces or countries have different laws on information storage and ownership, and that this might come into play with the involvement of long-distance caregivers.

Participants wanted to explore their involvement in the network in terms of their role and expectations. The interviews suggested it could be any member of a care team (service providers, family members, or the client) who should be charged with making sure the network is kept up-to-date in terms of information such as posting appointments. Two different setups arose from the interviews. Some participants felt that having a designated go-to person to make sure the network was updated would be the best way to ensure the network is kept up-to-date. Other participants thought that these kinds of tasks could be shared:

Service provider: And for that reason it lends itself to accountability, like everybody on that network who is providing care is accountable to the other members of the network so it's more cooperative, let's say, or collaborative. (Agency 3, group 2)

To determine how responsibility for updates would be determined, participants were interested in identifying how often updates should be posted. Frequency ranged from casually ("you could check it whenever"), to as often as daily. Service providers suggested that informal caregivers would likely be more active than the providers on the network. The idea of checking the network daily was expressed as an inconvenience by one participant. It was suggested that service providers could check up on a client's network prior to a home visit so they were aware of the care situation prior to entering the home:

Service provider: ... like you said, I have a lot of clients and I have to know what's going on from one – even in two or three days, I need to know what's going on and we're going to, you know, what I'm going to walk in to. (Agency 3, group 1)

Participants pointed out that if the network is in place, network members must keep their commitment to updating and checking the network. If they were not using the network frequently enough, it would defeat the purpose of having a network in the first place.

Linda: I know I wouldn't have time and people would be getting annoyed at me because I would never answer them or never share, and probably ask questions about a four week old post...(Informal caregiver)

During the interviews, it was suggested that if service providers had handheld devices such as tablets or smartphones, they could update the online network as they spoke with clients, similar to an electronic record. Other participants disagreed, stating:

Service Provider: Now I know what you're saying, but [a care] co-ordinator came in with this computer, sat it on the breakfast bar at the client's home, and didn't look at the client. [They] sat there and typed all their information. No, it's not right...And in my mind, that's not personal, good care. (Agency 2, group 1)

Many participants felt that using a computer while providing a home visit was inappropriate. They described that spending a large amount of time recording information took away from the care they were able to deliver during their home visit.

Finally, online networks may offer social features, such as providing updates about non-care related events and family activities. Service providers and case managers expressed that as professionals, they wanted to be clear that they would not become involved in the social aspects of online networks. They also suggested it would be important that these types of updates are filtered so that health care providers do not have to sort through these notifications in order to find relevant postings.

Service Provider: Because we have to be very clear that we would be involved in a professional clinical nature. It's not Facebook. We're not friends with them. After a discharge I don't – don't send me updates about where you're going and what you're doing. It's a professional involvement. That's how it differs from Facebook. We're not going to stay involved with them and see how they're doing and everything else. (Agency 1, group 2)

The boundaries between professionals and those involved on the network must extend into who may access the network. As described in the following section, health care professionals have restrictions to with which they may share information. For online networks to work there must be boundaries on who may access the network.

5.3.3 Resistance and Barriers to Use

Throughout the interviews, it was clear that most participants felt some level of resistance towards the use of online networks in home care. This resistance was based on discomfort with the technology of online networks, mandated boundaries, and the perception of having to complete more work without compensation. Participants predicted that with time, as younger generations begin to age, there would be a shift away from distrust of technologies.

Technology: Novelty and Anxieties-Discomfort with technology related to the nature of communicating through technology, and trust issues surrounding a novel method of communication. Concern was expressed by study participants, who suggested that the use of technology as a form of communication has the potential to replace in-person interactions that are essential to providing care.

Service Provider: I think one of my concerns too is...would be that I would be worried because everything was electronic that it would take away some of the necessity of the family to personally come and be involved with the client. Like everything would be done from a distance which would be...I'd substitute it for coming in hands-on kind of care. (Agency 1, group 2)

Participants were unenthusiastic about the perceived potential to diminish real-life interactions with other caregivers. A second common concern with using technology for communicating was the potential for misinterpretations with online communication. First, participants described having difficulty with expressing themselves through written text. Case managers agreed that they found it less difficult to communicate information to informal caregivers over the phone than over email.

Service Provider 1: It's harder to vent on an email.

Service Provider 2: Yes.

Service Provider 1: It is, you can't get anything across. (Agency 2, group 1)

These misinterpretations extended into a third concern with online communication.

Communicating through technology creates the potential for misunderstandings because nonverbal cues may be lost through text. This is a concern expressed by participants because service providers rely on these cues to determine whether the information they are receiving from informal caregivers and clients is correct.

Service Provider: And I think once it's in print, it looks official. So if the caregiver tells you or someone tells you and they're kind of stumbling through it, you can kind of guess "is it accurate?". It doesn't sound right. But once it's sort of arrives on print, it always sort of has more clout with it. (Agency 2, group 1)

Health care providers were concerned that they would be unable to discern how confident informal caregivers were about the information being posted because nonverbal cues are lost through the use of electronic communication. Case managers expressed concern for the potential of proliferating "creative diagnoses" through online network use. This means that the case managers were worried that informal caregivers or clients would search for symptoms online and self-diagnose, and then post unverified health information to the network.

Users of online networks must trust that the information posted on the network will not result in an information leak that puts the agency and the client at risk. These issues refer to the perceived privacy, confidentiality, and security that can be guaranteed with network use. Overall, participants approached the thought of posting sensitive documents (to the vault) with discomfort. Participants explained that they either did not trust technology enough to post these documents, or they did not see a

need for sharing this information. Specifically, the providers who should have access to these types of documents (legal or medical) would already have a copy of the information.

Marge: Um, care information I think would be good, but medical information, I don't know. I rely on my doctor. (Informal caregiver)

Due to the sensitive nature of information being posted by health care providers on the online network, participants wanted to make sure that this network was safe and secure to use; they would first need to trust the service.

Service Provider: It kind of reminds me of how our email works. Only certain people can access it if you have the access to it. So I kind of think that all that information could be from the vault and then the people privy to that information could go into there because somehow I understand that it's very, very secured because we just had examples of people's wills on here, medication lists, financials. Medical history. That's the stuff they wouldn't just put out anywhere and it'd have to be new so it would have to have some type of security for that. So think if it had that, it'd be great. (Agency 3, group 1)

Concerns about privacy, confidentiality, and security violations were prevalent in each interview. Participants were concerned that posting vulnerable information could be a risk to the client's need for privacy and confidentiality. Case managers felt that most informal caregivers and clients would not be comfortable posting their health information to the network. Sharing client information online places that information in the control of those who can access the network, rather than keeping information exclusively within the home care agency.

Service Provider: And we also have to know that that information is kept safely and securely and so if it was on someone else's network, we couldn't guarantee—we couldn't ... (Agency 3, group 2)

This goes back to the concept about concerns about who the network actually belongs to. Participants expressed reluctance to entirely trust the electronic service as security can never be entirely guaranteed.

Service Provider: I know they say things are secure but some, there's always somebody that's going to find a way... (Agency 3, group 1)

The perception that this service could be hacked creates a sense that the information posted online is never truly safe.

Boundaries Set by Governing Bodies -Prior to being able to use online networks in the home care setting, health care providers noted that they would first need to be supported and approved by their agency and by their regulating Community Care Access Centre.

Service Provider: If it comes down to if they, if we were to use [online network] as a tool, it would have to be adopted by the CCAC and they become in essence a bit of the administrator, like there is much more they use if they have to. Much like they use HPG or their DocuShare and all that kind of stuff that would be kind of, I think that way that they would be able to make it happen. (Agency 3, group 2)

Participants expressed concern that gaining approval from the agency might be difficult as they currently have other approved services for sharing information and they wish to avoid the potential for duplication of data and of work. In addition to receiving permission from regulatory bodies for network access, there are additional mandated and regulatory constraints that must be considered.

Linda: I was really surprised. [Home care agency] or CCAC won't do email. They're not allowed to. These are the people I'm working with. So the Tyze would be no good to contact these people; They're not allowed. I asked [service provider] "can you just email me stuff? Can I email you?" And she said "No, we're not allowed". (Informal caregiver)

Case managers at the CCAC were supportive of the online network but also expressed that their involvement would be minimal as they do not “micro-manage” their clients. They suggested that they were supportive of network use with personal support workers. Finally, regulating health care professional colleges place restrictions on the methods of communication used by health care providers to communicate with clients and families. If online network communication is not allowed by these colleges, this is a barrier to use.

Equating a New Service with More Work - The primary source of concern about the potential for online networks to be time consuming was that health care providers are very busy and do not feel they have time to commit to updating and checking online networks. They were unsure when they would be able to make time to update the networks because they are only paid to make home visits, and time spent outside of home visits for paperwork are hours that go unpaid.

Service Provider: I wonder from a time management point of view, if I have to go home at the end of the day, and do that on top of everything else I have to do, like, do I have to you know, start commenting on two or three people...(Agency 1, group 2)

Both service providers and informal caregivers who were less positive about network involvement expressed that they were unsure when they would have time to spend participating in the network. Some participants stated they did not think they would have enough time to use an online network to assist caregiving. Informal caregivers indicated this was because many were working full-time in addition to providing nonstop care to the care recipient. Service providers explained that they were reluctant to take on an additional task of updating networks unless there was a visible tradeoff and work was reduced elsewhere.

5.3.4 What’s in it for Me?

Service providers brought up a concept that they felt was important when introducing a new technology into their role: What’s in it for me? Participants who were able to see benefits to themselves

(whether their role was as a service provider or as an informal caregiver) spoke more positively about their potential interest in using an online service in home care. Concrete benefits that participants wanted to see from the use of an online service in home care were benefits to how they carry out their role as either a service provider or as an informal caregiver. Participants stated that they would need to benefit in terms of time-saving, without sacrificing convenience.

Service Provider: It might, it would add to our time though, right? It would be longer and right now, it's very hard to just even meet what we've got going on, right? With that, you know, again, if it was an easy, if it was easily populated and easily dealt with, you know, then it might be, it would be very useful, you can imagine. (Agency 2, group 1)

Throughout the interviews, there was an emphasis on the importance of network involvement in saving time and reducing work for participants. Service providers and informal caregivers who expressed reluctance to use online networks stated that they did not have enough time for such a service or that they perceived it as "another task".

Service Provider: It would be easy to go in there and like, "Oh, look, there's Mrs. B! Look! What she's doing now?" You know, and the caregivers may not pass that information on. But I know that there would be a great deal of benefit - but it's another step in your day, too, right? (Agency 2, group 1)

Interviewees stated that they could see online networks as helpful in saving money for the agency. Health care providers and informal caregivers alike do not want to use a service that is inconvenient. Participants stated they did not wish to take extra steps out of their day in order to use online networks unless there was a visible payoff.

Participants explained that there are home care agencies that require their service providers to have smart phones. This means that if the service was compatible with smartphone technology, providers would be able to access the service remotely.

Service Provider: Pretty well all companies hiring people now. They want people to have, you know, this on their smartphones. [Having the network remotely] would save a lot of frustration between family members and PSWs. (Agency 3, group 1)

Participants mentioned that they would use an online service if it was easy to use and part of this came through the convenience of using a smartphone to access the service from anywhere at any time.

Service Provider: I would say if it is easy to use and if it works in terms of lessening the burden of communication so that you don't have to enter it in there and also phone call and also related the same message so that you are not doing the same step twice. So if it is taking place of another step as opposed to making more work. (Agency 3, group 2)

Participants described the importance of convenience in the uptake of a new service such as an online network, but this alone is not enough for the adoption of a new technology.

Doug: It has to be convenient and it has to be easy, no question about that. You don't want it difficult or else they'll simply give up...The more simple and the easier you can make it the more use it would be to anybody. (Informal caregiver)

Interview participants discussed the need to see benefits from the use of a new technology before they would use it.

5.3.5 Testing the Water Before We Jump in

Participants stated that they would find it helpful to be able to pilot an online service before committing to its use. Although participants saw the potential for the use of online networks in home care, they pointed out that it would likely take time before something like this catches on. One participant drew a comparison to Youtube videos that "go viral". This participant explained:

Service Provider: ...It has to grow organically. Like, that's the thing with Facebook, with Twitter, with all of the things that are out there now; It wasn't really an incentive that got anybody to continue to use Facebook, other than "all my friend are on it, I need to find out what my friends are doing, I'm going to go on it". But who was it that took it to the place where "all my friends are on it"? It just happened to be the right place, the right thing at the right time. Same thing with Twitter - It just happened to be the right thing at the right time. (Agency 2, group 1)

Service providers and informal caregiver participants agreed that online networks may take time to catch on in home care. They suggested that this could be accelerated by giving potential users the opportunity to try out the service prior to committing to its use.

Doug: Give it time and if you offer a new situation or opportunity for people, they're going to try it, and if they like it they'll continue to use it. It's like everything else; you try something and if you like it you go with it, and if not you just let it go. I think that's what you're going to find with what you're studying or what you're trying to do; you're going to come up with a type of system that people are going to try and hopefully they find it successful for what they need it for and you'll find it gets more and more use once the word spreads. (Informal caregiver)

5.4 Navigation and Integration

The primary benefits of online networks as perceived by study participants were that these networks could improve communication between network members, and provide easy access and exchange of information. Specifically, users can "stay in the know" by having access to care

coordination tools, and information in one place. Informal caregivers are then better supported both socially and in caregiving.

5.4.1 Coordinating Care Through Better Communication

Participants described how currently, if home care is delivered to clients from multiple providers, they often have difficulty communicating with providers from other agencies. If the home care providers from separate agencies caring for the same patient were involved in the same network, they would be able to easily communicate across agencies without the difficulty of first finding the contact information of those other providers.

Service Provider: Because we share clients with other agencies like VON and that. So if they're on board with us as well for that, we'd be able to communicate with the PSWs from another agency about a client. It would be a huge, it would be ten times huge because in that situation, I do have to go to [the office administrator] and then she has to go to the supervisor usually at the other company—(Agency 3, group 1)

Communication disconnects were also described as occurring between providers from the same agency. Often, this leads to a situation where providers felt unprepared for their home visit because they did not have the proper information available prior to beginning their visit.

Service Provider: ...and it's hard for [care managers] or [office administrator] to always be contacting every single PSW and telling them about every single change because it's impossible. And so I can cause injury to a client then because we're not – we're misinformed. So I think it would help us to keep more informed. But I know a lot of people, PSWs have that frustration where they go in and they are like, what's going on. So I think it would keep us much more informed. (Agency 3, group 1)

Participants agreed that they liked the idea of using an online network to schedule and reschedule home visits. They thought it was helpful to have all individuals involved in care be able to see what kinds of services the client is receiving and on which days this would take place. One service provider described this as being useful because electronic copies do not get misplaced as do paper copies. For example, with dementia clients, they might discard the note. Online network use could prevent these kinds of issues.

Service Provider: Well, it could be good too because if the client has dementia and they take the calendar and they lose it, well, we can just go online then and look it up and we have a backup instead of trying to call the family. When's this supposed to be happening? (Agency 3, group 1)

A second use for the calendar was also relevant to dementia clients. In cases where the client may provide misinformation about scheduling, an “official” copy of their schedule posted online from informal caregivers may alleviate any confusion.

Service Provider: And there's a doctor's appointment this day, you know, because the person might get – we've had people say, oh, don't come tomorrow. I have a doctor's appointment and they really don't. (Agency 3, group 1)

Thirdly, this was discussed as being useful for coordinating care between multiple service providers who may not have another way of contacting each other. Participants appreciated that the option to show which care provider has claimed which care task should be useful. They suggested that it would create transparency between informal and formal care providers.

Service Provider: But it does just, in looking at the screens, it does look like that transparency is there, like it's sort of, is, on the positive side, nice to see, oh this goal has been set, oh this

goal is, you know, being taken care of by that person, sort of nice to have it laid out I guess.

(Agency 1, group 2)

Finally, the ability to contact many service providers and informal caregivers all at once was a feature of online networks that participants commented on positively.

Service Provider: You know, I was thinking when you, showing this, when my husband was in the hospital a couple of years ago, I would send out these broadcast email messages to a whole bunch. I made a contact group, but I was sending out these messages to a whole bunch of people, instead of doing that, I could have done something like this. (Agency 2, group 1)

5.4.2 Focusing on the Client Through Better Information-Sharing

Online network users are better able to stay in the loop because they have better access to care information. Sharing information in a single place was seen as beneficial because it makes information accessible to everyone involved in care, and therefore, allows informal caregivers to become more engaged in care. By designating a single space for information to be updated, families and service providers do not have to make sure they check several places to gather all the correct information for tasks such as scheduling.

Online networks can be used to create a care environment that focuses on the client's needs. Client needs surrounding home care can be addressed by providing a place for service providers to work together.

Service Provider: I think for the client even if they're not actually doing it right the [online network] piece they could give some feedback. I could see that it could have some potential benefit for them feeling very much like there is a team. You that work hard for them and it's not just like when we come in and the left hand doesn't know what the right hand is doing, we

pretend we are a team but we're not, you know. Well, we work in relative isolation so for the client, they can really feel that there is a team working on it. (Agency 1, group 1)

Participants suggested it would be helpful to share strategies for caring for a specific client. They could post what has worked for them and what has not. The example given by a service provider to describe this was that certain care tasks are more difficult to perform on some clients. Different service providers could share advice with each other as well as with informal caregivers on how they approach these challenges.

Service Provider: ...Or even like I know I had one client where we had an issue with a lift that she had. And I was hearing that I was the only one feeling uncomfortable and not doing this right so if I could have talked to one of the other PSWs or something and said well, what are you doing that I'm not. Or find out are you actually, like is it just the client saying I'm the only one or – it would have made me feel more comfortable, I think, of just hearing it from someone else that, no you're not the only one. (Agency 3, group 1)

Online networks could be used to share client information with family members such as information pertaining to equipment needs, updates on the client's health status and changes in medication. This use of online networks allows informal caregivers to clarify information of which they feel unsure. A health care provider described this concept as follows:

Service Provider: It kind of acts as a double insurance. Even though you might call the family, maybe they forgot that it wasn't, maybe you said to them on the phone, they could always then go back later and look it up. (Agency 3, group 1)

Care requirements change as a result of the client's deteriorating condition. Informal caregivers are not always able to remember how to address changing needs and having available information can help alleviate these problems.

All participant groups described online networks as a way to have easier access to information related to medications. Discussions about the implications of online networks in medication management were generally positive. Participants suggested that online networks could be useful in keeping track of which medications the client is taking, if there are changes in medications, if medications need to be filled, or if they have remembered to take their medications. In the following excerpt, a service provider describes a hypothetical situation where a pharmacist has access to the network.

Service Provider: So every time they get new medication, the pharmacist uploads a new form, then all you have to do is take a look on there to see the new updated medication. Talk about med reconciliation! (Agency 2, group 1)

This also allows families to become actively engaged in care conversations and allows them an opportunity to have their input through the online community. This type of service was perceived as allowing clients and families to have both a voice and an active role in the care they receive. The following dialogue between two participants describes this:

Service Provider 1: And for that reason it lends itself to accountability like everybody on that network who is providing care is accountable to the other members of the network so it's more cooperative, let's say or collaborative.

Service Provider 2: And I could also see if you had the type of client who was tech savvy, liked to feel that they were self-directing everything, I think they would enjoy this.

Service Provider 1: Yes, for sure. Like participating in their care.

Service Provider 2: Participating in their care and being in control of it. (Agency 3, group 2)

Informal caregivers are able to gain the sense that there is a team working on their care with them because of the active input they are able to receive and contribute to if they had their health care

providers involved in the network. All groups agreed that this aspect of online network use would only be helpful if information was kept current.

5.4.3 Supporting Informal Caregivers

Along with sharing information about the client with the family, participants perceived online networks to be a place where information about the client's health conditions and community support resources could be provided. This allows informal caregivers to have a better understanding of their care recipient's health condition. One participant used diabetes as an example of this:

Service Provider 1: You know, things like diagnosis, let's say it's a diabetic person, so we put you, you know, information of diabetes and what to look for and so the family would see that and that would be... (Agency 3, group 1)

This extends beyond posting information, and was seen as a place to create a dialogue between informal caregivers who have questions and service providers who have the answers.

Doug Something happens; something comes up, "Is this normal? Can I find out from somebody? Is there some way I can help improve the situation? Is there someone who can guide me or is there some information as to the aspects of what's going on that could help me understand it?" There's, you know, unlimited number of things that could pop out for people depending on the situation in their home and whatever [the] person they're looking after needs. For example, the type of stroke that [spouse] had is common but it affects everybody totally differently - everybody is affected in a complete different way. (Informal caregiver)

Participants perceived online networks as a way of engaging informal caregivers in care. Caregivers may become more engaged in care because they are given a direct way of accessing

information pertaining to the care recipient. Online networks were seen as a method to provide social support to informal caregivers or the client themselves.

Service Provider: for your mom it might just be a social thing she might enjoy doing it, it might give her something to do, especially if she is house bound. (Agency 1, group 1)

Participants often described online networks as a way to enhance social connectedness for informal caregivers. In response to being asked who would benefit from the use of an online network, an informal caregiver responded:

Mary: Someone who really needs that social contact, the emotional back-up. Ideas about how to care for their person...I think the contact with other people and the sharing of ideas, um, and sort of letting, you know that you are not alone in this and, um, there are people out there that you can reach out to. (Informal caregiver)

Finally, participants were asked if they saw online networks playing a role in any aspect of care transitions.

5.4.4 Supporting Transitions

The use of an online network creates an environment where all the client information is stored in a single location. Participants perceived this to be useful as it meant that as information is added to the network, a client history is made.

Service provider: I think it would help me do a more thorough job if we were able to understand the client and their history like if there was some history on there as well that would be helpful. Yeah you don't get any information on the referral and you get what you get from the client so that could help me get a better picture of the clients. (Agency 1, group 1)

Participants stated that this history could be useful in preparing a client who may be required to transition into long-term care.

Service Provider: So for home to a long term care facility, even, like, they could go in and they could see the client's likes, dislikes. You know, if they had dementia and they can't convey all that, then they know, you know. And then they have the history. Can you imagine someone's at home, they're on that network, so all this... [information] they're putting into it, and then they go into a long term care facility, and the family says, "We're on this network, we're giving you permission to go in and take a look at all the stuff that Mom's been doing" without having to sit down and gather information. (Agency 2, group 1)

Case managers agreed that online networks could be used as an electronic charting system to facilitate information exchange during care transitions. Although participants did not see a place for online networks to help facilitate hospital-to-home transitions if they were not already in place, they felt that the client history created through the use of online networks would be helpful in preparing a client who may be transitioning into long-term care.

5.5 Discrepancies Between Groups

During the case manager focus group sessions, the interview data mirrored the information obtained from service provider focus group interviews. However, during the course of the case manager interview, attitudes shifted from an overall positive impression of the online network, to feeling more cautious about use. Participant attitudes seemed to shift in response to a strong voice in the interview. The strong voice expressed concerns about the potential for social aspects of the online network to dominate network use, and distract from non-social care aspects that case managers felt they should respond to exclusively. This created a flow of comments regarding the seemingly social nature of the online network, and subsequent discussion on whether case managers did indeed perceive their involvement on the network as useful. This shift was demonstrated in the pre- and post-survey

questionnaires, where many respondents shifted from positive perceptions of online network use in home care, to responses that showed uncertainty.

**CHAPTER 6: DISCUSSION, CONCLUSIONS, AND NEXT
STEPS**

6. 1 Summary of Findings

Overall, participants shared mixed feelings about the use of online networks in home care. Although they perceived many of the network's features positively, participants also had many questions related to network use. Service providers and case managers had several questions about the extent to which they would be expected to become involved in the networks. The biggest concerns shared by service providers, case managers and informal caregivers were related to privacy, confidentiality, and security. Participants were hesitant to trust that the information that might be posted to the networks will be safe from third party viewers. Although they did not entirely trust the technology, they felt that younger users, who they perceived as being more comfortable using technology, would be both more likely to trust the network and feel more comfortable with posting sensitive information online.

Participants agreed that online networks could be an effective and efficient way of communicating and sharing information between service providers of the same agency, between different agencies, between service providers and informal caregivers, and between informal caregivers. Better communication could improve the way care is delivered by enabling more effective communication and information sharing, thus keeping informal caregivers more engaged in care and keeping service providers more informed about the client's care.

Participants described the importance of being able to try out the network and receive training before committing to use. Participants suggested that a pilot and trial of online networks in home care by intended end-users would be useful in assisting service uptake. The pilot could enable a practical examination of the topics that came up during the interview. The study findings have been compared with the five characteristics important in the adoption of technology (Table 4).

Table 4: Diffusion of Innovation Characteristics (Rogers, 1995) and Study Findings

	Relative Advantage	Compatibility	Complexity	Trialability	Observability
Positive	<ul style="list-style-type: none"> • Information posted in one place • Asynchronous • Notes posted online cannot get lost or thrown out • More convenient than phone calls • Everyone can be contacted at once • Easier way to contact other service providers and informal caregivers • Client history is created with use • -potential cost-savings 	<ul style="list-style-type: none"> • This may help workflow • Will service providers/Informal caregivers need to go out of their way to access/use the service • Addresses unmet needs: Social support informal caregivers • Facilitates client- centered care • Facilitates continuity of care • Supplement information available during care transitions 	<ul style="list-style-type: none"> • Easy to use (?) • Short time to learn (?) • Available training (?) 	<ul style="list-style-type: none"> • Pilot study • Trial sessions 	<ul style="list-style-type: none"> • Seeing how this benefits other service providers/informal caregivers
Negative	<ul style="list-style-type: none"> • Takes time to learn to use • Associated costs • Privacy and security issues • You may not know if messages are received 	<ul style="list-style-type: none"> • This may hinder workflow • Dislike of computers • Computer illiteracy • No perceived need for social support • Service providers are unpaid for time spent on network • May violate current communication/privacy regulations • Ownership of health information may be shifted • Creates more work 			

6.2 Participant Overview

Diffusion of Innovation theory (Rogers, 1995) separates technology users into five unique categories based on their characteristics and the likelihood that they will adopt a technology at a certain period in time: innovators, early adopters, early majority, late majority, and laggards. Informal caregivers felt that although they saw online networks as being useful, they did not see themselves using it, as they are not engaged in technology the way younger generations are (perceived to be). Service providers said they would use online networks once they could see the benefits and feel that the service was trustworthy. Case managers agreed that the online network would be helpful, but they did not feel they will be active participants in these networks. Based on these kinds of responses, it is likely that the majority of participants in this study were neither innovators nor early adopters (the categories accounting for those who are likely to adopt technology early-on). This may in part offer some explanation for the resistance in using technology in home care, specifically with aspects surrounding privacy, confidentiality, and security.

6.3 Current State of Affairs

The findings suggest that although current forms of communication are working, there is room for improvement. An important piece in the diffusion of innovations is the perceived need for the new technology (Rogers, 1995). Currently, informal caregivers communicate with service providers through hand-written notes and telephone calls, while emails are less common and sometimes prohibited. Service providers from the same agency communicate with one another using email, telephone, or face-to-face, however, communicating with other agencies is more difficult. Service providers were often unaware of other agencies involved in client care or they did not have their contact information. In addition, participants felt that communication could be improved by becoming more consistent. For example, sometimes service providers were unsure of the client's health status until they entered the home. Service providers prefer to have information about the client ahead of time. Miscommunications such as missed calls and lost notes were an additional source of frustration for participants. These issues

indicate a gap in home care communication and information sharing. These issues are less common for retired informal caregivers who are able to be home during service provider visits. As a result, these participants were more satisfied with the communication aspect of home care. The findings from this study suggest there is an opportunity for communication and information-sharing in home care to be more reliable, efficient, flexible and convenient. Posting care information in a single place could be useful to alleviate the concerns around miscommunication, errors, service utilization, and ED visits as it would set a precedent for how communication takes place in home care. Service providers and informal caregivers are currently restricted to communicating in ways that require them both to be available at the same time (phone; face-to-face), or in the same place within a short amount of time (notes, which require either party to be present in the client's home). Theories on technology uptake and use state that uptake depends in part on the perceived usefulness and relative advantage of the service in respect to the existing alternative (Rogers, 1995). Participants were able to see an opportunity to improve on their current method of coordinating care through the features offered by the demonstrated online network. These improvements were mostly related to aspects of time and cost-savings. The more visible these benefits are, the more likely online networks will be rapidly adopted in home care (Rogers, 1995). This suggests that there is an opportunity for online networks to fill certain gaps that are currently not being met in home care.

6.4 Making the Rules and Setting Boundaries

There were specific circumstances where participants thought that the use of online networks would be especially helpful. The findings point to the usefulness online networks may have in the delivery and management of complex care. Specifically, participants said they could see online networks being used by informal caregivers of clients who are receiving care over a long period of time. Larger networks require more coordination as there are more people involved sharing more tasks. In this case, the network serves two purposes; the coordination of care and provision of additional support to primary caregivers, who are more likely to suffer from caregiver burden as a result of

providing more intense care (Keating et al., 2003). In these examples, the client might not be an active participant in the network due to physical or cognitive incapability. Instead, the online network would function to support the informal caregiver network in working with service providers to enhance care coordination. In contrast, participants did not believe online networks would benefit caregivers of clients who are dealing with acute and mild conditions. Acute and mild conditions are often associated with higher levels of independence for the client, in addition to briefer, less intense involvement from informal caregivers and service providers. These findings suggest that there may be more of a need for online networks in certain care dynamics.

The findings reveal a common perception that older caregivers are less likely to be interested in using online networks to support care. Participants associated older age with computer illiteracy and anxieties surrounding the use of technology. Contrary to these perceptions, research indicates that females over the age of 55 are the fastest growing demographic of internet users (Berger, 2000 *cited in* Chen & Persson, 2002). The demographic of fastest growing internet users overlaps with the majority of informal caregivers, who are females over the age of 45 (Pyper, 2006). This suggests that while online networks may be inappropriate for those who are computer illiterate, they may be impactful for a larger portion of informal caregivers than was suggested during the focus group interviews. Participants who do not enjoy using the computer as a pass-time were less receptive to the concept of online networks in home care, which speaks to the compatibility aspect of Diffusion of Innovation (Rogers, 1995).

If online networks are used in home care, the agency will need to assist in subsidizing network costs. Online networks could be offered as an optional service provided by the agency, and would be subsidized until the agency's relationship with the family ended. Service providers are concerned about the level of commitment that is expected from them if they become involved in the online networks of home care clients. In contrast, other participants suggested that if service providers see benefits resulting from online network use such as time-saving, cost-saving, and convenience, they are likely to

be more supportive of this technology. In sum, before committing to becoming involved in online networks, service providers want to know what is expected of them in order to determine if the service is compatible with their current workflow and service/job expectations (Rogers, 1995). The findings from this study point to the importance of making sure parameters of use are clear and familiar to both service providers and informal caregivers.

Service providers were interested in discussing network ownership. There are concerns over who controls access, and who is responsible for the [health] information posted on the networks. Currently, paper documents are stored by the agency; however, when information is posted online, anyone involved in the network will be able to access and store this information as well. These concerns are not unique to technology in home care; as pressure increases on the health care system to use technology, health information ownership discussions have moved to the forefront of the policy agenda when discussing electronic health information (Hall & Schulman, 2009; Kendall, 2007; Komito 1998). The ability to store health information in multiple locations (on multiple computers) leaves more opportunity for inappropriate information storage, access, and use, and spreads the responsibility of protecting health information across the entire care network. This highlights the importance of addressing health information ownership concerns when using services that place health information into the hands of multiple providers and caregivers.

Informal caregivers did not discuss these issues to the same degree as service providers. There are a variety of reasons that this could be the case. Service providers must deal with a diverse range of clients and informal caregivers, while informal caregivers are only familiar with their own care network or a limited number of care networks in which they may be involved. This may allow service providers to more speculative about issues that may arise with informal caregivers based on numerous experiences. These kinds of concerns may also be familiar to service providers, who have professional obligations and regulations to which they must comply on a day-to-day basis, while informal caregivers are accessing online networks for personal reasons that do not carry the same legal implications. This

may also be simply because of a small sample size of informal caregivers (saturation not reached) who by chance are not concerned with network logistics.

The resistance to using online networks in home care is linked to participant distrust of the network, regulatory boundaries set by governing agencies, and the concern about having more work. During the focus group interviews, the researcher found it challenging to move the conversation past concerns surrounding privacy, confidentiality, and security and onto discussing the potential use and benefits of the online network. These concerns are both prevalent and appropriate when considering the use of a new technology, especially within a health care context. Fox and Raine (2000) demonstrate that 60% of all internet users are uncomfortable with posting their medical records online, because there is perceived potential for this information to be stolen. The findings from this study parallel those by Fox and Raine (2000); participants were concerned that they would not have control over information once it was posted to the network. These concerns are common, and are exacerbated when users do not know who is receiving their information on the other end, or how it is being used (Kendall, 2007; Luo & Najdawi, 2004). These concerns can be addressed by creating clear guidelines about how patient information may be used when it is accessible electronically (Kendall, 2007). Online banking and health care are often compared in these types of discussions, as online banking has become popularized in recent years while health care lags behind (Ball & Gold, 2006). In online banking, even with safeguards in place, breaches in security occur and privacy of confidential information is at risk. These findings highlight the importance of using strategies to ensure that the online network is as secure and confidential as possible (see: next steps).

Participants felt that certain dimensions of electronic communication would be inappropriate for proper delivery of home care. First, they pointed out nonverbal cues, an important component of face-to-face communication, would be lost when users post messages to the online network. These cues are important to service providers when discussing sensitive information about the client with informal caregivers. They were also concerned that using online networks to communicate with

informal caregivers might replace in-person interaction, reducing interactions to online “transactions”. This is a concern because service providers felt that face-to-face care and communication are an important part of their role as service providers. While it is true that nonverbal cues are lost in online interactions, electronic communications have been shown to give quieter members from a group the opportunity to become active contributors, and therefore, may play a role in engaging informal caregivers to act as care partners (Bordia, 1997; Burgoon, Bonito, Ramirez, Dunbar, Kam & Fischer, 2002). Electronic communication does not replace face-to-face interactions; in fact, those who communicate electronically tend to have more social ties than those who do not (Wang & Wellman, 2010).

A second barrier to using online networks in home care comes through policies set by regulating bodies, such as the College of Nurses of Ontario, on how service providers are permitted to communicate with clients and family members. Service providers are currently not permitted to discuss clients or informal caregivers by name with other service providers while in public. As well, they are not able to contact clients or informal caregivers through email unless contact is first initiated by the clients or informal caregiver. Even then, they may not use names. Participants are concerned that these kinds of regulations would make it difficult to use an online network because it would violate set policies and procedures around client confidentiality; while service providers are not permitted to discuss client care openly, online network involvement would enable the entire network to know about the service providers’ involvement. These findings speak to the importance of addressing policy-level issues when introducing technology in home care as well as into other sectors of the health care system (Kleine, 2006; Miller & Sim, 2004). The existing regulations on communication have special implications in the case that caregivers outside of the care recipient’s province become involved in providing care alongside service providers using online networks, as different regions may have different laws on privacy (Kleine, 2006).

Service providers and informal caregivers were concerned that becoming involved in an online network would be too time-consuming and create work rather than efficiencies. Again, this barrier is not unique to online networks in home care, and is often discussed in the context of gaining support from physicians to use electronic medical records (Campbell, Sittig, Ash, Guappone, Dykstra, 2006; McAlearney, Schweikhart, Medow, 2004; Miller & Sim, 2004). There may indeed be initial workflow and time costs associated with learning to use a new service, even if there are definite long-term benefits of a similar nature. This speaks to participants' perception of the network's relative advantage (Rogers, 1995). In this case, time-consuming work may initially deter informal caregivers and service providers from becoming involved in the online network. The potential for cost and time saving over a longer-term may need to become visible prior to widespread adoption in home care agencies. For informal caregivers, training and comfort using an online network may be necessary to support use.

Service providers and informal caregivers who could not perceive a personal benefit from the use of online networks were less receptive to the possibility of using them. During interviews, the expression "what's in it for me" was used. For service providers this may range from perceiving the online network as a better way to do their job, having cost and time-saving incentives, coupled with convenience and ease of use. These findings echo similar findings from studies investigating how to encourage health information technology uptake (Blumenthal, 2009; Miller & Sims, 2004). For informal caregivers, benefits may be through the ability to provide more-informed care, or additional social support (Schaefer, Coyne & Lazarus, 1981). Karavidas and colleagues (2005) conducted a study investigating how computer usage may affect older adults. They found that computer knowledge was associated with higher life satisfaction in older adults, and suggested this finding may be linked to gaining access to additional facets of social support for both clients and informal caregivers.

Providing end-users the opportunity to test online networks without a commitment could potentially encourage uptake. These suggestions are supported by the diffusion of Innovation theory (Rogers, 1995), which describes trialability as a component in determining the uptake of a technology.

Therefore, it would be useful for agencies to offer training or trial sessions for informal caregivers and service providers who are interested in using online networks to enhance the care they provide. This could help make the online network to be more user-friendly (Rogers, 1995). Additionally, service providers would need to understand the potential incentives to use online networks, specifically in the form of time, cost, or effort savings. Participants suggested that this could be done through training sessions and free trials.

6.5 Navigation and Integration

The theme “Navigation and Integration” explores the features of online networks that study participants perceived as having the most impact. Participants felt that using online networks would help them to coordinate care through improved communication for all users. Participants noted that using an online network for communication would be a better alternative to communicating using the telephone in certain contexts. Currently, service providers have difficulty contacting other members of their care network due to mismatched availability. They suggested that online communication would alleviate these issues because the network may be checked and updated anytime. The asynchronicity of caregiver networks has been shown to be beneficial to caregivers, who may be too busy to check their network at regular hours because of the demands of providing care, family commitments, and work demands (Owens & Robbins, 1996). In addition, service providers may use this to communicate with one another, in order to enhance client-centred and integrated care. Service providers across agencies sharing care for the same client could become better informed about the other service providers, what one another has been doing, and how they can be reached in order to refine care plans and services. Additionally, the online network may help overcome contextual barriers to forming important informal-formal relationships; informal caregivers may use the service provider’s visit as an opportunity for respite outside of the home, while maintaining frequent contact using the network (Gantert et al., 2009).

Participants agreed that online networks would be useful for sharing information. Information about the client's conditions and appointments were often suggested as items that would be useful to share in order to help coordinate care between providers and to help informal caregivers keep track of the client's care. There was some disagreement over whether medication information should be shared on the network. Participants who were supportive of sharing this information suggested that this would be a useful way for service providers to access a list of medications that the client is taking, to become notified of any changes in medications or when medications have been taken or need to be refilled. The reduction of medication errors is crucial, especially in chronically ill older adults who may be managing multiple medications (Ellenbecker et al., 2004). Using online networks as a centralized place for information sharing may reduce the opportunity for medication errors if all information regarding medication changes is posted. For this to be effective, network users will need to trust that the online network and any information posted are secure.

Based on the online demonstration, participants saw networks as a way of addressing issues in continuity, including following a consistent care plan, relationship-building with providers, and having information available and complete (Haggerty et al., 2003). The online network is able to store communication history, share information on the client and caregiver needs, and update network members on the client's changing health status.

Informal-formal relationships are important because they contribute to the informal caregiver's understanding and ability to provide care and make care-related decisions with competence, confidence, and support, thereby lessening the burden of care (McWilliam et al., 1999; Ward-Griffin & McKeever, 2000). These benefits are bidirectional; by forming a positive relationship with informal caregivers, service providers are able to get additional needed information related to the client (because history and informal conversations are stored), thus further improving continuity of care (Sims-Gould & Martin-Matthews, 2010; Ward-Griffin & McKeever, 2000). Inadequate information-sharing has historically been contributed to poor informal-formal collaboration (Laitinen & Isola, 1996). If online

networks are able to improve continuity of care, there may be important implications for improved delivery of home care services to older adults, and to better caregiver outcomes.

Participants agreed that online networks could play a role in enhancing available emotional and social support to informal caregivers. This support could come from better communication and others helping with taking the client to appointments and knowing when help is needed to support the primary caregiver. Online networks were seen as helpful because they may be able to assist in creating a supportive team approach to care. The importance of social support in informal caregiver well-being is considerable (Grant, Elliott, Giger & Bartolucci, 2001; Marziali & Donahue, 2006; Schaefer et al., 1981; Stewart et al., 2002). Again, online networks provide an additional dimension of convenience for receiving support for caregivers who may not have the option of accessing other forms of support during regular business hours due to work and caregiving commitments (Stewart et al., 2002). As an online network will be accessed by multiple people, it may allow network members to support one-another when face-to-face meetings and telephone conversations may not be possible. The addition of service providers to these networks adds a valued dimension of support that allow caregivers to feel empowered as they provide care to care recipients (Clemmer et al., 2009).

Online networks were perceived by study participants as being beneficial due to the history created through postings (everything is stored in one place over a long period of time). If information posted to the network is kept over a period of time, participants felt that this would be useful for keeping the entire network informed of the client's health trajectory. The stored information would be especially useful if the client transitions into a long-term care home or another care setting. Current research suggests that the amount of client information during transitions is inadequate (Coleman, Parry, Chalmers & Min, 2006; Toscan, Mairs, Hinton, & Stolee, 2012). Care transitions are a vulnerable time for both informal caregivers and clients, who may be faced with unexpected role demands or health status changes in a short amount of time. As such, it is crucial that sufficient client health information is available during these times (Coleman et al., 2006; Given, Sherwood & Given,

2008). The history provided by the use of the online network, as well as supportive documents posted by service providers, could potentially contribute to addressing the information gap during the transition from home to long-term care or other settings. Additionally, clients requiring long-stay home care service may be more complex, requiring numerous transitions in and out of home care. Although transitions in and out of hospital were described as being rushed, if an online network was in place, participants agreed that the information available from the pre-existing network would be helpful.

6.6 Continuity of Care

The study findings indicate that online networks may play a role in enhancing continuity of care for home care clients in the home care setting and as they transition into other settings. First, participants anticipated that the network would allow client information to be posted in one place and accessed by care providers and information caregivers. This relates to the concept of informational continuity (Haggerty et al., 2003). Informational continuity is especially challenging when caring for a client who is complex and receiving care from multiple providers who may not be known to one another (Reid, Haggerty & McKendry, 2002). This study found that participants expected online networks to be particularly helpful for managing clients who are a part of complex care networks, for whom informational continuity is especially important. Participants agreed that the online network would be a useful tool for enhancing communication and familiarity between service providers and informal caregivers (and clients, should they be included in the network) thereby helping to enhance relational continuity (Haggerty et al., 2003). Management continuity, which refers to the consistency and timeliness of the care plan over time, was a common issue in the study findings. Aspects of management continuity that were discussed included allowing all caregivers (formal and informal) to have access to the care plan, medication needs and task claiming, in addition to enhancing care transitions. Reid and colleagues (2002) explain that the case manager role is a designated position for ensuring that management continuity exists for clients or patients. This contrasts with findings from the case manager focus group, as case manager participants did not feel they managed care in the same

level of detail that would be required through online network involvement. See Table 5 for a summary of study findings in relation to continuity of care.

Table 5: Continuity of Care as it relates to study findings from the theme “Navigation and Integration”

Informational Continuity	Management	Relational
<p><i>Having documented information about the client available, including information on medical events, preferences, support available, values, care context (Reid et al., 2002)</i></p> <ul style="list-style-type: none"> • having correct client information available before visit • having correct client information available in one place (electronic charting) • having information available regarding the client’s preferences (such as food preferences) • client history created over time 	<p><i>Having a consistent and timely care plan available with all service providers involved in the plan over time (Reid et al., 2002)</i></p> <ul style="list-style-type: none"> • cross-agency communication • all information available to everyone at once regarding client care updates • scheduling is all in one place • claiming care tasks (reduce duplication) • sharing strategies on managing particular client’s condition • medication management • addressing client’s changing needs for care due to condition deterioration • enhance informal caregiver’s understanding of client’s condition • scheduling and rescheduling home visits 	<p><i>Contact between provider, informal caregiver, and client that is reliable, predictable and consistent (Reid et al., 2002)</i></p> <ul style="list-style-type: none"> • keeping informal caregivers informed regarding the client’s needs • supporting informal caregivers; answering questions about care • clarifying informal caregiver uncertainty • posting supportive information for informal caregivers (e.g., on disease) • giving informal caregivers a voice • communication between informal caregivers and clients using networks • mass-communication • knowing who is involved in care

6.7 Commentary on the Current System and Health Care Provider Communication

Participants' exploration of their perceptions on the use of online networks to provide care revealed an additional aspect of communication issues among health care providers. For example, in the subtheme *focusing on the client through better information-sharing*, service providers revealed that they felt that online networks could help create the sense that providers are working on care as a team rather than as isolated units. Service providers are aware that they are not always working as a team; however, there is not a sense that this is an urgent issue. Service providers elaborated to say that they currently do not have the contact information of other providers from separate agencies caring for a common client. Information is not available upon home entry for service providers. This suggests that service providers are aware of communication and information breakdowns in the health care system, but respond to these as though they are "par for the course". It is disconcerting that service providers do not see these aspects of care as urgent system-level shortcomings, as the consequences of communication and information breakdowns in health care continuity are widely documented (Coleman et al., 2006; Cortes, Wexler & Fitzpatrick, 2004; Van Walraven et al., 2008; Woodward et al., 2004).

The theme "What's in it for me?" suggests that for service providers, personal benefits also act as a motivator for deciding whether to use a service to enhance care such as an online network. This theme may serve as an indication that current practice does not always recognize client and caregiver needs as key priorities and underscores the need to refocus on client-centred care.

Some study findings appeared to be contradictory. For example, there is a contrast between the concept of adding detailed medical information to the network and the major concerns about privacy risks as a result of even minimal network involvement. This could indicate that the issue of supporting online network use in home care is not straightforward, and potential users will need to weigh potential costs of network use with perceived benefits.

These findings bring to light the need to bridge organizations in the health care system so that they can optimize care through better information sharing and communication, as well as the need to bring clients and caregivers to the centre of care.

6. 8 Strengths and Limitations

Due to timeline and recruitment constraints, this study was limited to a small sample size. This study used multiple informants for rigour; however, due to agency constraints on recruitment, saturation was not reached for case managers or informal caregivers. Findings for these two groups were similar to those of service providers, and future research should aim to further explore perceptions of case managers and informal caregivers on technology use in home care to see where discrepancies may exist. Guest and colleagues (2006) found that for studies using purposive sampling to conduct interviews, saturation is generally reached at 12 interviews, although the groundwork for major themes can emerge with as few as six interviews. This number may increase if the participants are less similar to one another (Morgan, 1992 *as cited in* Morgan, 1996). Therefore, it is unlikely that with four interviews of informal caregivers, saturation was reached. The consequences of this is that this study was unable to cover a wide range of informal caregiver perceptions, making it difficult to predict how other informal caregivers may respond to the online network demonstration. Informal caregivers come from a diverse range of care predicaments and because this study did not target a particular condition, network size, or informal caregiver/client demographic, it is difficult to accurately assess the interview findings for informal caregivers. Without either targeting a specific informal caregiver group, or including a large sample of caregivers, the findings for informal caregivers are incomplete and future research should address these shortcomings. In this study, informal caregiver participants had small care networks, few service providers, or lived with the care recipient, therefore, the study was unable to explore perceptions of those informal caregivers who have larger networks and more service providers with whom they must coordinate care. This raises questions as to the number of informal caregivers that need to be interviewed before saturation can be confidently reached. Future research will need to focus

on informal caregivers to address this. In relation to the case manager focus group, although many of the findings echoed those of the service provider group, it is difficult to determine whether this group reflects the attitudes of other case manager groups. For focus groups, saturation is generally reached after four to six groups have been conducted, when the interviewer is able to accurately predict interview points (Glaser & Strauss, 1967). Due to organizational and timeline constraints, only one group of case managers was interviewed. Consent to audio-record was not received from this group; therefore, data richness was lost because specific wording of ideas was not retained. Fortunately, this interview was similar to the interviews conducted with service providers. In order to determine if case managers do indeed have similar perceptions of online networks as service providers, it is recommended that future research includes more individuals from this subgroup. Service providers and case managers work with many different care situations and dynamics, and were able to draw on these experiences during the interviews to describe where they felt online networks would be a good fit. In contrast, informal caregivers are only familiar with their own predicament and may have found it difficult to picture how online networks might be used in other situations beyond themselves.

Next, there were limitations presented with the study populations chosen by the researcher. All informal caregivers were recruited through the WWCCAC, and as a result, may be different than the types of participants recruited through not-for-profit groups, such as the Alzheimer's society. Only one of the four informal caregivers interviewed was available for a face-to-face interview. The remaining three interviews were conducted over the telephone. As a result, the researcher was unable to attend to nonverbal cues such as facial expressions from these participants. In addition, because informal caregivers were unable to meet in a focus group interview, the benefits of group dynamics, such as building off each other's ideas, were untapped. Because the researcher could only speak English, participants were required to be fluent in English in order to participate. This could have led to the exclusion of other demographics with entirely different perceptions on online networks in home care. Only one participant was male. This could lead to a bias in participant perceptions. The reality of

caregiving is that the majority of informal caregivers and service providers are female (Glazer, 1988), so the imbalanced population distribution may have played a role in the difficulty recruiting male participants. Fortunately, there are benefits from phone interviews that are useful for research. For example, this allowed the researcher to speak with informal caregivers who may have not otherwise been able to participate in the study due to transportation or time constraints.

Service providers were based in different cities: Kitchener-Waterloo, London, Hamilton, and Toronto. This could be a limitation as this may be responsible for inconsistencies in participant perspectives. Future research should aim to either focus on the use of online networks in a variety of cities (with many participants) to see how city dynamics play a role in network use, or should focus on a single region in order to gain a deeper understanding of the network's potential in one area.

This study used a video demonstration to show participants the features of a specific online network, Tyze. Participants were unable to interact with the online network; therefore they were unable to provide a first-hand review of their perceptions on the use of this kind of online network. Future research should allow participants to either interact with the network, or use it for an extended amount of time in the form of a pilot study.

6.9 Conclusion and Next Steps

In conclusion, informal caregivers, service providers, and case managers perceive online networks as a positive and useful addition to home care services and there are specific instances where they felt that online networks would be particularly useful. Although participants are satisfied with some aspects of current care delivery and communication, they felt there were some areas where improvements could be made. They explicitly stated an online network would not be useful for all care situations or for all informal caregivers. They suggested online networks may be most appropriate for informal caregivers providing care to complex clients who have chronic conditions and a large network of care. Online networks could help to keep long-distance caregivers informed.

Study participants agreed that online networks had a role to play in enhancing continuity of care and care coordination within home care and transitions into long-term care, and from hospital (if the network exists already). Participants agreed that online networks would be useful in enhancing navigation and integration, through better information sharing, communication, social support, and engagement of informal caregivers. The networks would be most useful at keeping the entire care network up-to-date on relevant care information and preparing clients and families for transitions into long-term care, should they occur.

The study uncovered a variety of barriers related to the implementation of online networks in home care, as well as possible facilitators in overcoming these barriers. Participants who were reluctant to use online networks in home care felt they would not have enough time, or it would not fit in with their current lifestyle/workflow. In addition, there were safety concerns relating to privacy and confidentiality associated with the use of online networks. Case managers felt that their involvement in online networks to manage care would be minimal, but felt that the networks would be useful in connecting service providers with informal caregivers. Before becoming involved, service providers were interested in knowing how much networks would cost and how this would be covered, how long networks would last and who would control the network. Participants were interested in being able to see how they would benefit in their role from using online networks. Deciding on boundaries and parameters for network use and information sharing that adhere to agency and regulatory body requirements would help facilitate online network adoption and would allow service providers and case managers to feel more at-ease with using the network.

The findings reflect the literature on introducing new technology into an organization or to an individual. Before online network use can be widely accepted, it will take time. Steps that can be taken to facilitate online network uptake in home care for both service providers and informal caregivers are

providing education and training about how to use such networks, and the benefits that may arise through use. Before end-users will adopt a service to enhance informal-formal networks, they will need to perceive benefits from use.

In order for online networks to find a place in connecting informal caregivers and service providers, the researcher makes the following recommendations based on the study findings.

For individuals who wish to use an online network but are anxious about using technology or are computer illiterate, concerns can be addressed with proper training (Czaja & Rubert, 2002; Hill & Weinert, 2004). Training would also be useful for those who are comfortable using technology but may not know how to access the network specifically.

Participants were uncertain about trusting online networks with their information for fear of the potential for security or confidentiality breaches. In the context of this study, confidentiality refers to the steps taken to keep an individual's health information private. To address privacy concerns, data can be encrypted, computers can be stored in an area inaccessible to the public (GMC, 2000 *as cited in* Kelly & McKenzie, 2002). Agencies can go over a consent or waiver form outlining the terms of use for the network. Security keys or passwords can be used to control access, and as with home care agency emails, these passwords can be changed at pre-determined time intervals.

The online network that was demonstrated to participants, Tyze, offers a feature, the Vault, which allows only certain members to access certain information. In addition, it may be useful to disable file copying and perform regular privacy audits of the network transactions. A potential solution that would allow boundaries to be set on network usage would be a waiver and consent form for all network members to sign. This would produce an agreement regarding how the service providers and informal caregivers are permitted to interact with and use the network. Network users could agree to use only pseudonyms or identification numbers if they felt it would further protect their privacy.

Educational sessions could help network members understand the safety features offered by the online network and potential consequences if these are violated.

A system-level solution would be to change payment for service providers so that they have monetary incentives to use online networks. Miller & Sim (2004) look to future policy changes, as well as standardized procedures for privacy and confidentiality in order to address barriers similar to those presented in this study but involving electronic medical records by physicians. Policy changes may include those that provide incentive for use, or adjustment to communication regulations. For example, removing restrictions on electronic communication for service providers would be a big step to creating an environment supportive of using technology to enhance care.

Although the findings from this study support the perceived use of online networks in home care, more research is needed to determine how online networks can be used to facilitate care between service providers and informal caregivers, as well as how to receive support from governing agencies who mandate how service providers may communicate with clients and families. Future studies should look to include more informal caregivers, specifically those who are involved in large-scale networks and who enjoy accessing the internet on a day-to-day basis. A pilot study that invites service providers and informal care networks to connect using an online network would be useful to identify how the findings of this study translate into practice. A pilot study could investigate the success of an online network to enhance care for both primary care and home care. For example, the study could focus on the use of online networks in home care, or the service could be based out of primary care if it were to be offered through a family health team. In this case, other care providers who may not be providing care through the home, such as physiotherapists and dietitians who are accessed outside of home care services would be able to choose to contribute to the care network. This would ensure that service providers involved in the study are interested in using the network during the pilot. Informal caregivers could be recruited through service providers who are participating in the study. Informal caregivers should have easy access to a computer and the internet in order to be able to use the network

effectively. Based on the findings from this thesis study, it would be useful to ensure that informal caregivers of individuals with dementia and other cognitive impairments, diabetes, and other complex chronic conditions are included for study, as well as those with large and complicated care networks.

Future research can look to addressing barriers to implementation using the facilitators suggested by this research. There is emphasis on the need to address concerns surrounding trust of technology before online networks can proliferate in home care. A pilot study would be useful to measure benefits and costs of actual network usage over a period of time. This type of study will be useful in addressing any unexpected issues that may arise when networks are put into practice in the future.

Before end-users decide whether they will adopt or reject a technology, it is important they are given the opportunity to try the online network themselves, or see how others (colleagues; friends) use the network (Rogers, 1995). This will allow them to further and more concretely develop their perceptions of the network in relation to the five characteristics important for the adoption of technology (Rogers, 1995). A pilot study exploring the use of online networks to connect caregivers and service providers will likely play a large role in determining the success of online networks in home care.

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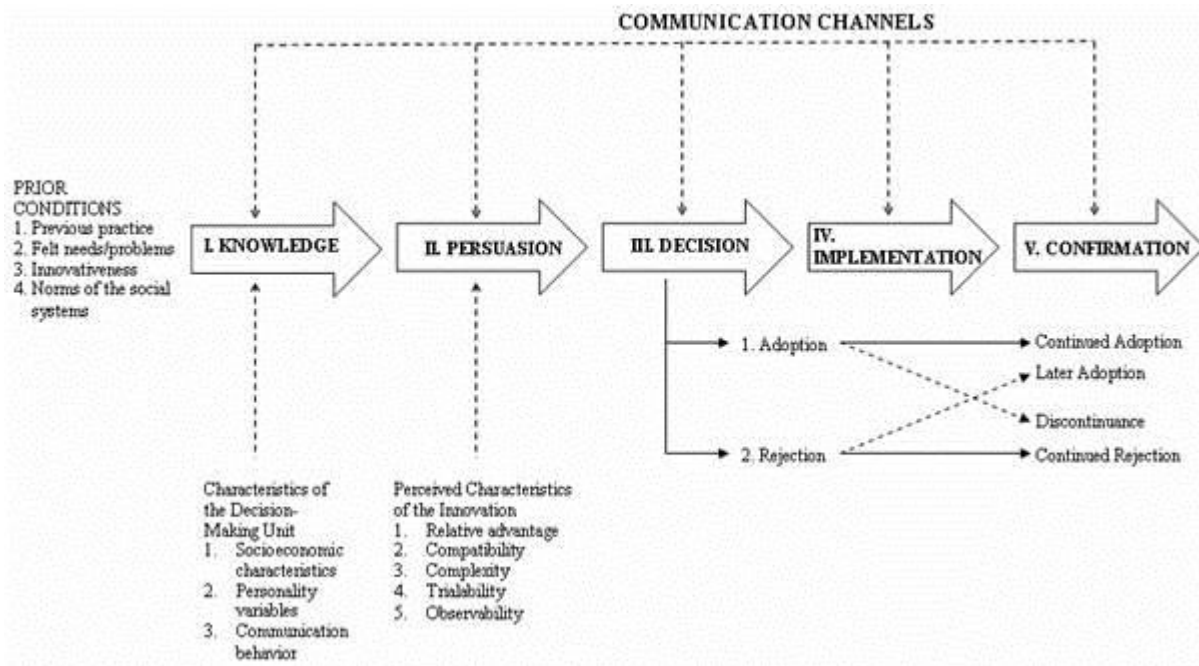
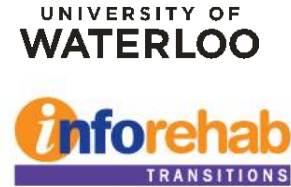


Figure 1- Diffusion of Innovation Theory – Model of Stages (Rogers, 1995)



APPENDIX A
Home Care Case Manager
Engagement and Consent



Date:

Study Name: Caregiving in the information age

Researchers:

Dr. Paul Stolee, PhD

Associate Professor

University of Waterloo

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Phone: 519-888-4567 ext 35879 **Email:** stolee@uwaterloo.ca

Emily Piraino, MSc candidate

University of Waterloo

200 University Ave W, Waterloo, ON N2L 3G1

Phone: 519-888-4567 ext 35879 **Email:** epiraino@uwaterloo.ca

Introduction

You are being asked to give your permission to participate in a research study called “Caregiving in the information age” conducted by two researchers: Dr. Paul Stolee and Emily Piraino.

Your participation in this study is entirely voluntary, so it is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what the research involves. This consent form will tell you about the study. It will explain why the research is being done; what specifically you are being asked to do; and the possible benefits, risks and discomforts.

Please take time to read the following information carefully.

Who is conducting this study?

This study is being conducted by two researchers: Dr. Paul Stolee and Emily Piraino, both who are from the University of Waterloo. Our study is funded by a Canadian Institutes for Health Research (CIHR) emerging teams grant.

Background

Tyze is a specialized online networking tool aimed at building personal networks of care. Tyze networks provide innovative ways to communicate and share information. A Tyze network is a group of individuals often brought together around a person, called the center of the network. The network is created online by a ‘connector’ – an individual who acts as the administrator and coordinator of the network. All networks are goal driven – they are intentional communities. Individuals, such as family members, friends and neighbors, are invited to join the network and help achieve its’ goals.

What is the purpose of the study?

We are interested in learning about how Tyze networks can be used by CCAC clients, informal caregivers of CCAC clients, and CCAC staff members.

The main questions that this research seeks to answer are:

1. Do participants perceive Tyze as a useful resource for caregivers?
2. Do participants perceive Tyze as having the potential to help clients transition smoothly through the health care system?
3. What barriers and opportunities exist for Tyze as a caregiver intervention?

What am I being asked to do?

You are being invited to participate in a focus group led by one of the researchers. With your permission, the interview will be audio-recorded. The interview will begin with a verbal overview of the networking tool, followed by a written questionnaire that will take no longer than 5 minutes to complete. Next, we will show you a visual online demonstration of the various features of a Tyze network.

We will be asking you demographic information if consent is given; however, the information you provide will be used as part of a larger analysis and will not be traceable to you. This will take place during a phone interview prior to the focus group.

We will then ask that you help us address our first research question by sharing your broad opinion and experiences using technology in a health context, and more specifically your view on the feasibility of using a Tyze network within your daily work at the CCAC. We want your help to understand some of the potential barriers and opportunities you would expect in the use of this technology. This conversation will take place either as an individual interview, or as a focus group interview, which will be scheduled at a convenient location and/or time for you. The conversation will be led either in-person or over the telephone by one or both of the researchers and will last for up to one hour. Face-to-face interviews and focus group interviews will finish with a final written questionnaire that will take no longer than 5 minutes to complete.

What are the Risks and Discomforts?

We do not think there will be any risks or discomfort from your participation in the research.

What are the benefits of the research and benefits to you? No one knows whether or not you will benefit from this study. There may or may not be direct benefits to you from taking part in this study.

Voluntary Participation: Your participation in the study is completely voluntary and you may choose to stop participating at any time. Your decision whether or not to participate has no effect on your employment with the CCAC now or in the future. You can decline to participate in the study without penalty. If you agree to participate, you will be able to talk about whatever you are comfortable with. If there is an interview question you don't want to answer, you may say, 'I don't want to answer that question.'

Withdrawal from the Study: You can stop participating in the study at any time, for any reason, if you so decide. Your decision to stop participating, or to refuse to answer particular questions, has no effect on your employment with the CCAC now or in the future. If you decide to leave the study, all of the data collected from you will be immediately destroyed wherever possible.

Confidentiality: All information you give during the research will be held in confidence. Your data will be kept in a locked filing cabinet at the University of Waterloo School of Public Health and Health Systems, and will be accessible only by the members of the research team. Your name will not appear

on any data. Only the project team (Dr. Paul Stolee and Emily Piraino) will have access to entire interviews. Data will be kept for five years and then confidentially destroyed.

You will be explicitly asked for consent for the use of audio data for the purpose of reporting the study's findings. If consent is granted, these data will be used only for the purposes associated with teaching, academic or health care conference presentations, publications, and/or sharing with other researchers and you will not be identified by name. With your permission, anonymous quotations from the group or individual interview may be used in publications. Quotations used may be attributed to your role in caregiving (e.g., case manager), however, no other identifying information will be provided with quotations used.

Confidentiality will be provided to the fullest extent possible by law.

Questions about the Research? If you have questions about the research in general or about your role in the study, please feel free to contact Dr. Paul Stolee either by telephone at (519) 888 4567 x35879 or by e-mail (stolee@uwaterloo.ca) or Emily Piraino either by telephone (519) 888 4567 x35879 or by email (epiraino@uwaterloo.ca)

This research has been reviewed and has received ethics clearance by the University of Waterloo Office of Research Ethics. If you have any questions about this process or about your rights as a participant in the study, please contact Susan Sykes, Director, Office of Research Ethics, University of Waterloo at 519-888-4567 ext. 36005 or ssykes@uwaterloo.ca.

Conclusion

We are excited about this study and look forward to gaining your insight on Tyze personal networks. We sincerely hope that you will consider participating.

CONSENT FORM

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by **Emily Piraino** of the Department of **Health Studies and Gerontology** at the University of Waterloo, under the supervision of Professor **Paul Stolee**. I have had an opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses.

I am aware that I may allow audioclips in which I speak to be used in teaching, scientific presentations, publications, and/or sharing with other researchers with the understanding that I will not be identified by name.

I am also aware that excerpts from the survey and/or interview may be included in the thesis and/or publications to come from the research, with the understanding that quotations will be either anonymous or attributed to me only with my review and approval.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher. This project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

Yes No

I agree to have the in-person interview and any follow-up telephone conversations audio-recorded.

_____ Yes _____ No

I agree to let audio clips be used for presentations of the research results.

_____ Yes _____ No

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

_____ Yes _____ No

I agree to the use of direct quotations attributed to me only with my review and approval.

_____ Yes _____ No

Please indicate your position at Waterloo-Wellington CCAC:

Participant Name: _____(Please print)

Participant Signature: _____

Witness Name: _____(Please print)

Witness Signature: _____

Date: _____

Date

When this study is completed, we will write up a summary of the results. Would you be interested in receiving a copy?

Yes, please email me a summary of results. My email address is:

Yes, please mail me a summary of results. My mailing address is:

No, I do not wish to receive a summary of results

What is your gender?

- Male
- Female

What is your age?

- 18 years or younger
- 19-24 years
- 25-34 years
- 35-44 years
- 45-54 years
- 55-64 years
- 65-74 years
- 75 years or older

What is your current role?

How long have you worked in your role?

- Less than 1 year
- 1 to 5 years
- 6 to 10 years
- Over 10 years

What is the highest level of education you have completed?

- Grade school
- Some high school
- High school graduate
- Some college / technical school
- Completed college / technical school
- Some University
- University undergraduate degree
- Some Post-graduate school
- Post-graduate degree
- Prefer not to say

Survey Instructions

Please take 5 minutes to complete this brief questionnaire outlining your views of health technology. Your responses will provide important information that will allow us to gain a better understanding of how health care providers view technology in the context of health.

Your responses will be both completely anonymous and completely confidential; however, you are in no way obligated to complete this survey. You may skip any questions you do not wish to answer. The information you provide will be kept confidential and identified by number only. Data collected will be kept securely stored in a locked office for a period of 5 years, and then confidentially destroyed.

This survey will provide you with the opportunity to share your thoughts on patient social networks and where you feel you and others in health care provider positions fit in the context of these networks.

Steps

1. Do not write your name or any other personal identifiers on the questionnaire sheet.
2. Circle an answer that you feel most accurately represents your thoughts towards a particular statement or question.
3. Feel free to add any additional comments or concerns in writing at the end of the questionnaire.
4. Once you have completed the questionnaire, place it in the envelope given to you.

Answer the following questions by circling or checking off the response that you feel is most appropriate.

1. How often do you currently use technology to assist you when you work with clients and families?
 - Very frequently
 - Frequently
 - Occasionally
 - Rarely
 - Never

2. I would be willing to use technology to communicate with home care clients.
 - Strongly Agree
 - Agree
 - Undecided
 - Disagree
 - Strongly Disagree

3. Technology has the potential to contribute to family caregiving in a positive way.
 - Strongly Agree
 - Agree
 - Undecided
 - Disagree
 - Strongly Disagree

4. Technology has a place in addressing issues in continuity of care.
 - Strongly Agree
 - Agree

- Undecided
- Disagree
- Strongly Disagree

5. Technology that allows caregivers to communicate and network with health care providers has the potential to contribute to transitional care in a positive way.

- Strongly Agree
- Agree
- Undecided
- Disagree
- Strongly Disagree

APPENDIX D
Interview/Focus Group Guide:
Home Care Case Managers/Service Providers

SECTION 1: Welcome

a) For Focus Group:

Hello and welcome to the focus group. This focus group will last for about 1 hour or less. The aim of the focus group is to get everyone's input on the potential for Tyze to be used within your day-to-day role at [agency]. Questions will be based on the information you received in the participant engagement and consent letter. We will give everyone a chance to speak. We value everyone's opinion and would appreciate if there are no interruptions while others are speaking.

OR

b) For Interview

Hello and thank you for taking the time to speak with me today. This interview will last for about 60 minutes and I'll be talking about your views on the Tyze support tool that was explained and demoed to you during the participant engagement session.

SECTION 2: Consent

With your permission, I will be audio-recording this session and making notes based on our conversation. All the information gathered will be used for the purposes of this study only and no names will be used in the summary reports. The tapes will be destroyed once the study ends. We ask that you please keep confidential any information shared during this conversation.

(Pre-demonstration questionnaire will be administered here – Appendix B)

SECTION 3: Feedback based on Participant Engagement Session

What was your overall impression of the online demonstration?

Probe: Was the information clear? Easy to follow?

Is there anything you think you could be improved about the session?

What was the best part of the session?

What are some ways that you think people are using Tyze?

(Probe for specific examples, by whom, when, for what purposes)

SECTION 4: Overall Impressions of Tyze for use in Care

Overall, what are your general impressions of the Tyze networking tool? (Probe for positive and negative aspects of Tyze in general)

Based on what you have learned so far, how might you use Tyze within your role at the CCAC? (Probe for specific opportunities: who would you communicate with, what features would be useful)

- a) Is there anything in particular that excites you about Tyze?
- b) Is there anything in particular that concerns you about Tyze?

How do you think it would help your clients? Their families? Their caregivers?

Can you think of someone who might use Tyze? Probe for specific examples.

SECTION 5: Tyze during transitions

Overall, can you see Tyze playing a role in achieving smoother transitions from hospital to home/ home care? Why or why not?

Do you see Tyze as a potential solution to issues with continuity of care for clients? Why or why not?

SECTION 6: Implementation at [agency]

What barriers or roadblocks do you think exist for using Tyze with clients and families?

How do you think the use of this sort of networking tool would impact the services you provide to clients and/or their families at [agency]?(Probe for both positive and negative outcomes)

What do you see as being the overall benefit(s) to the CCACs of providing Tyze to clients and/or their families?

SECTION 6: Use of Technology in a health context

What types of technologies do you currently use to **communicate** with others in your day to day role at [agency]? (Probe: computer, email, blackberries, social networking tools)

- a) How do you communicate with other staff members? (Probe for any challenges)
- b) How do you communicate with clients and family members? (Probe for any challenges)

Is there a technology that you wish you could use with clients and families? Why?

How do you think technology could be better used in our health care system? With home care?

SECTION 7: Concluding questions

Do you have any questions about what we have discussed?

Thank you for your time and valuable contributions to this project. [see if you can follow up with details about a pilot study to see if they are interested in participating]

APPENDIX E
Post-demonstration
Questionnaire for Case
Managers/ Agency

Survey Instructions

Please take 5 minutes to complete this brief questionnaire outlining your views of health technology. Your responses will provide important information that will allow us to gain a better understanding of how health care providers view technology in the context of health.

Your responses will be both completely anonymous and completely confidential; however, you are in no way obligated to complete this survey. You may skip any questions you do not wish to answer. The information you provide will be kept confidential and identified by number only. Data collected will be kept securely stored in a locked office for a period of 5 years, and then confidentially destroyed.

This survey will provide you with the opportunity to share your thoughts on patient social networks and where you feel you and others in health care provider positions fit in the context of these networks.

Steps

1. Do not write your name or any other personal identifiers on the questionnaire sheet.
2. Circle an answer that you feel most accurately represents your thoughts towards a particular statement or question.
3. Feel free to add any additional comments or concerns in writing at the end of the questionnaire.
4. Once you have completed the questionnaire, place it in the envelope given to you.

Answer the following questions by circling or checking off the response that you feel is most appropriate.

1. I would be willing to use technology to communicate with home care clients.
 Strongly Agree
 Agree
 Undecided
 Disagree
 Strongly Disagree
2. Technology has the potential to contribute to family caregiving in a positive way.
 Strongly Agree
 Agree
 Undecided
 Disagree
 Strongly Disagree
3. Technology has a place in addressing issues in continuity of care.
 Strongly Agree
 Agree
 Undecided
 Disagree
 Strongly Disagree

4. Technology that allows caregivers to communicate and network with health care providers has the potential to contribute to transitional care in a positive way.
- Strongly Agree
 - Agree
 - Undecided
 - Disagree
 - Strongly Disagree

APPENDIX F

TELEPHONE SCRIPT: RECRUITMENT OF FAMILY CAREGIVER PARTICIPANTS

Hello my name is _____. I am calling from the (Waterloo-Wellington) Community Care Access Centre. We want to know if you would like to participate in a research study being conducted by researchers at the University of Waterloo. We are looking for family caregivers to gain their insight and their opinions towards online patient networks geared at providing support for family caregivers. We want to show you a demonstration and have your feedback on how you see you and other caregivers using this type of service, if at all. We will be using your feedback in conjunction with feedback from health care providers to determine whether the involvement of health care providers in personal networks is a feasible strategy for addressing issues in caregiving often experienced by caregivers and their friend/family member during caregiving – particularly when it concerns caring alongside other home care providers. The study involves taking part in a 1.5 hour focus group. This focus group will be scheduled for **DATE OF FOCUS GROUP**. The focus group will be held on campus at the University of Waterloo or other central location in a private room. Your decision to participate is voluntary and will in no way impact the care you receive from CCAC home care staff, as this study is being directed by the University of Waterloo and not the CCAC.

This study has been reviewed by, and received ethics clearance through, the Office of Research Ethics, University of Waterloo. However, the final decision to participate is yours.

Are you interested in hearing more about the study and possibly participating?

If Yes:

We are able to provide you with an information letter that provides further details about the study. What would be the best way for us to send this information to you? (e.g., email, fax, mail, whichever is most convenient). Do you give consent for researchers from the University of Waterloo to contact you regarding this study?

Do you have any questions?

Also inform them of the following:

- You may decline to contribute to any part of the focus group you do not wish to participate in and may terminate the focus group at any time
- The interview will be tape recorded to facilitate collection of information, and later transcribed for analysis.
- All information you provide will be considered confidential, be stored in a secure location, and disposed of after 5 years.

If No: Thank them for their time.

APPENDIX G

Family Caregiver Engagement Information and Consent: Informal Caregivers



Date:

Study Name: Caregiving in the Information Age

Researchers:

Paul Stolee, PhD

University of Waterloo

200 University Ave W, Waterloo, ON N2L 3G1

Phone: (519-888-4567 ext 35879)

Email: stolee@uwaterloo.ca

Emily Piraino, MSc candidate

University of Waterloo

200 University Ave W, Waterloo, ON N2L 3G1

Phone: (519-888-4567 ext 35879)

Email: epiraino@uwaterloo.ca

Introduction

You are being asked to give your permission to participate in a research study conducted by two researchers: Dr. Paul Stolee and Emily Piraino.

Your participation in this study is entirely voluntary, so it is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what the research involves. This consent form will tell you about the study. It will explain why the research is being done; what specifically you are being asked to do; and the possible benefits, risks and discomforts.

Please take time to read the following information carefully.

Who is conducting this study?

This study is being conducted by two researchers: Dr. Paul Stolee and Emily Piraino are from the University of Waterloo. Our study is funded by a Canadian Institutes of Health Research Emerging Team Grant.

Background

Tyze is a specialized online networking tool aimed at building personal networks of care. Tyze networks provide innovative ways to communicate and share information. A Tyze network is a group of individuals often brought together around a person, called the centre of the network. The network is created online by a 'connector' – an individual who acts as the administrator and coordinator of the network. All networks are goal driven – they are intentional communities. Individuals, such as family members, friends and neighbors, are invited to join the network and help achieve its' goals.

What is the purpose of the study?

We are interested in learning about how Tyze networks can be used by CCAC clients, informal caregivers of CCAC clients, and CCAC staff members.

The main questions that this research seeks to answer are:

1. Do participants perceive Tyze as a useful resource for caregivers?

2. Do participants perceive Tyze as having the potential to help clients transition smoothly through the health care system?
3. What barriers and opportunities exist for Tyze as a caregiver intervention?

What am I being asked to do?

You are being invited to participate in a focus group led by one of the researchers. With your permission, the interview will be audio-recorded. The interview will begin with a verbal overview of the networking tool, followed by a written questionnaire that will take no longer than 5 minutes to complete. Next, we will show you a visual online demonstration of the various features of a Tyze network. The session will take place either in-person, or over the telephone, and may take place in a group setting or on an individual basis. The decision regarding the format of the session will be made according to geographic location, convenience and your preference.

We will then ask that you help us address our first research question by sharing your broad opinion and experience using technology in a health context, and more specifically your view on the feasibility of using a Tyze network within your own unique care situation. We want your help to understand some of the potential barriers and opportunities you would expect in the use of this technology. This conversation will take place as an individual interview or as a focus group interview led by one or more of the researchers and will last for approximately 60 minutes. Face-to-face interviews and focus group interviews will finish with a final written questionnaire that will take no longer than 5 minutes to complete.

What are the Risks and Discomforts?

We do not think there will be any risks or discomfort from your participation in the research.

What are the benefits of the research and benefits to you? No one knows whether or not you will benefit from this study. There may or may not be direct benefits to you from taking part in this study.

Will I receive remuneration for my participation in the study?

For your participation in the study you will receive a gift card redeemable at Chapters valued at \$25. You will still receive a gift card if you choose to withdraw from the study prior to study completion. The amount received is taxable. It is your responsibility to report this amount for income tax purposes.

Voluntary Participation: Your participation in the study is completely voluntary and you may choose to stop participating at any time. Your decision whether or not to participate has no effect on your relationship with the CCAC now or in the future. You can decline to participate in the study without penalty. If you agree to participate, you will be able to talk about whatever you are comfortable with. If there is a question you don't want to answer, you would just say something like, 'I don't want to answer that question.'

You will not be paid to participate in this study.

Withdrawal from the Study: You can stop participating in the study at any time, for any reason, if you so decide. Your decision to stop participating, or to refuse to answer particular questions, has no effect on your relationship with the CCAC now or in the future. If you decide to leave the study, all of the data collected from you will be immediately destroyed wherever possible.

Confidentiality: All information you give during the research will be held in confidence. Your data will be kept in a locked filing cabinet at the University of Waterloo School of Public Health and Health Systems, and will be accessible only by the members of the research team. Your name will not appear on any data. Only the project team (Dr. Paul Stolee and Emily Piraino) will have access to entire interviews. Data will be kept for five years and then confidentially destroyed.

You will be explicitly asked for consent for the use of audio data for the purpose of reporting the study's findings. If consent is granted, these data will be used only for the purposes associated with teaching, academic or health care conference presentations, publications, and/or sharing with other

researchers and you will not be identified by name. With your permission, anonymous quotations from the group or individual interview may be used in publications. Quotations used may be attributed to your role in caregiving (e.g., family caregiver), however, no other identifying information will be provided with quotations used. Confidentiality will be provided to the fullest extent possible by law.

Questions about the Research? If you have questions about the research in general or about your role in the study, please feel free to contact Dr. Paul Stolee either by telephone at (519) 888 4567 x35879 or by e-mail (stolee@uwaterloo.ca) or Emily Piraino either by telephone (519) 888 4567 x35879 or by email (epiraino@uwaterloo.ca)

This research has been reviewed and has received ethics clearance by the University of Waterloo Office of Research Ethics. If you have any questions about this process or about your rights as a participant in the study, please contact Susan Sykes, Director, Office of Research Ethics, University of Waterloo at 519-888-4567 ext. 36005 or ssykes@uwaterloo.ca.

Conclusion

We are excited about this study and look forward to gaining your insight on Tyze personal networks. We sincerely hope that you will consider participating.

CONSENT FORM

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by **Emily Piraino** of the Department of **Health Studies and Gerontology** at the University of Waterloo, under the supervision of Professor **Paul Stolee**. I have had an opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses.

I am aware that I may allow audioclips in which I speak to be used in teaching, scientific presentations, publications, and/or sharing with other researchers with the understanding that I will not be identified by name.

I am also aware that excerpts from the survey and/or interview may be included in the thesis and/or publications to come from the research, with the understanding that quotations will be either anonymous or attributed to me only with my review and approval.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher. This project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

___ Yes ___ No

I agree to have the in-person interview and any follow-up telephone conversations audio-recorded.

___ Yes ___ No

I agree to let audio clips be used for presentations of the research results.

___ Yes ___ No

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

___ Yes ___ No

I agree to the use of direct quotations attributed to me only with my review and approval.

___ Yes ___ No

Participant Name: _____(Please print)

Participant Signature: _____

Witness Name: _____(Please print)

Witness Signature: _____

Date: _____

When this study is completed, we will write up a summary of the results. Would you be interested in receiving a copy?

Yes, please email me a summary of results. My email address is:

Yes, please mail me a summary of results. My mailing address is:

No, I do not wish to receive a summary of results

APPENDIX H
Interview/Focus Group Guide:
CCAC Family Caregivers

SECTION 1: Welcome

Hello and thank you for taking the time to speak with me today. We'll be talking about your views about Tyze, the online tool that was explained and demoed to you in the participant engagement session.

SECTION 2: Consent

With your permission, I will be audio-recording our conversation and making notes. All the information gathered will be used for the purposes of this study only and no names will be used in the summary reports. The tapes will be destroyed once the study ends.

(Pre-demonstration questionnaire will be administered here)

SECTION 3: Feedback based on Participant Engagement Session

What was your overall impression of the online demonstration?

Probe: Was the information clear? Easy to follow?

Is there anything you think you could be improved about the session?

What was the best part of the session?

What are some ways that you think people are using Tyze?

(Probe for specific examples, by whom, when, for what purposes)

(Post-demonstration questionnaire will be administered here)

SECTION 4: Potential to Use Tyze within Individual Care Situation

Overall, what are your general impressions of the Tyze networking tool? (Probe for positive and negative aspects of Tyze in general)

What are some of the ways you think you might be able to use Tyze? (Probe for who would be involved in the network, specific features that would be useful or not)

Is there anything in particular that excites you about Tyze?

How do you think it would help you or someone you know? How would it benefit you or someone you know?

Is there anything in particular that concerns you about Tyze?

If you were to use Tyze, what kinds of roadblocks or barriers do you think you might run into?

SECTION 5: Overall Impressions of Tyze for Use in Formal/Informal Care

On some Tyze networks, people have paid staff, such as home care workers or their doctors on their network. What do you think of this? [probe for what conditions would need to be met for them to be comfortable with this?]

Can you think of ways that Tyze could be used to improve home care?

Do you think Tyze could be used to improve communication with health care providers? Relationships? If yes, how? If no, why not?

Do you see any potential roadblocks to using Tyze for families? For paid staff?

SECTION 6: Tyze during transitions

Overall, can you see Tyze playing a role in achieving smoother transitions from hospital to home/ home care? Why or why not?

Do you see Tyze as a potential solution to issues with continuity of care (this means sharing information with different health care providers and yourself)? Why or why not?

SECTION 7: Overall benefits for (CCAC/[agency 1])

Do you think there would be benefits of (CCAC/agency 1) offering Tyze networks to clients? To families?

What do you think would be some of the benefits? What would be the challenges or roadblocks? [probe for how it could be a benefit or contribute to carer-provider-patient relationships and act as an additional touch point of care]

Can you see yourself using Tyze? In what ways? With other family? With care providers?

SECTION 8: Use of Technology in a health context

Do you currently use any type of technology to help with caregiving? Your health? (probe for mobile apps, social networking sites, ipads, etc.)

What do you use it for?

Is there a technology that you wished existed to help you with your caregiving? Health?

What types of technologies do you use to **communicate** with others in your day to day activities? (Probe: computer, email, blackberries, social networking tools)

Do you use any forms of technology to communicate with health care providers? (probe for doctor, physiotherapist, dentist, etc.)

How do you think technology could be better used in our health care system? With home care?

SECTION 9: Concluding questions

1. Do you have any questions about what we have discussed?

Thank you for your time and valuable contributions to this project. [Discuss with participant the pilot study and see if they are interested in having you send more information about the next phase of the study]

Participant ID Number

Who is the person receiving home care in relation to participant?

- Husband
- Wife
- Mother
- Father
- Mother-in-law
- Father-in-law
- Child
- Grandmother
- Grandfather
- Friend
- Other: _____

In what year was your [relative] born?

19_____

What is his/her living arrangement, do they live: [check all that apply]

- Lives in their own home/apartment
- Lives with respondent
- Lives with another relative, describe: _____
- Lives in assisted living
- Lives in a seniors home
- Other arrangement: _____

[If relative does not live with respondent:]

Where do you live in relation to your [relative]? [PROBE: approximate distance, travel time]

Would you consider yourself to be the person who has the most responsibility for their care?

Yes No

b.) If yes, how long have you been providing care to your [relative]?

c.) If no, who has the most responsibility? _____

Are you the sole caregiver for your [relative]?

Yes No

How long has your [relative] been receiving care from a personal support worker? (Probe: years or months)

How many hours a week does your [relative] receive personal support services?

In what year were you born?

19_____

What is your gender?

- Male
- Female

How long have you been caring for [care recipient]

- Less than 1 year
- 1 to 5 years
- 6 to 10 years
- Over 10 years

How many hours per/week do you spend caring for care recipient?

When you need help to care for [relative] who do you ask?

When you need help to care for [relative] how do you go about getting this help?

What do you consider being your main ethnic or cultural origin?

What is the highest level of education you have completed?

- Grade school
- Some high school
- High school graduate
- Some college / technical school
- Completed college / technical school
- Some University
- University undergraduate degree
- Some Post-graduate school
- Post-graduate degree
- Prefer not to say

Please select the option that best describes your marital status.

- Single, never married
- Living with a significant other
- Married
- Separated
- Divorced
- Widowed
- Prefer not to say

Please select the option that best describes your employment status

- Full-time
- Part-time
- Retired
- Other

APPENDIX J

Participant Engagement Information and Consent: Agency 1

Date:

Researcher:

Emily Piraino, MSc candidate

University of Waterloo

200 University Ave W, Waterloo, ON N2L 3G1

Phone: 519-888-4567 ext 35879 **Email:** epiraino@uwaterloo.ca

Introduction

You are being asked to give your permission to participate in a research study conducted by researcher: Emily Piraino.

Your participation in this study is entirely voluntary, so it is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what the research involves. This consent form will tell you about the study. It will explain why the research is being done; what specifically you are being asked to do; and the possible benefits, risks and discomforts.

Please take time to read the following information carefully.

Who is conducting this study?

Emily Piraino is from the University of Waterloo. Our study is funded by Human Resources and Skills Development Canada (HRSDC).

Background

Tyze is a specialized online networking tool aimed at building personal networks of care. Tyze networks provide innovative ways to communicate and share information. A Tyze network is a group of individuals often brought together around a person, called the centre of the network. The network is created online by a 'connector' – an individual who acts as the administrator and coordinator of the network. All networks are goal driven – they are intentional communities. Individuals, such as family members, friends and neighbors, are invited to join the network and help achieve its' goals.

What is the purpose of the study?

We are interested in learning about how Tyze networks can be used by clients, informal caregivers of clients, and staff members.

The main questions that this research seeks to answer are:

1. Is it possible for people receiving services from [agency 1], their informal caregivers, as well as staff to use an online personal network tool called Tyze?
2. What is the impact of using tyze personal networks on clients, their informal caregivers, and staff?

What am I being asked to do?

You are being invited to participate in a Tyze *participant engagement session* led by one of the researchers which will first include a verbal overview of the networking tool, as well as a visual online demonstration of the various features of a Tyze network. You will also be asked to fill out a short demographic questionnaire about your role at [agency 1]. The session will take place either in-person, or over the telephone, and may take place in a group setting or on an individual basis. The decision regarding the format of the session will be made according to geographic location, convenience and your preference.

Next, we will ask that you help us address our first research question by sharing your broad opinion and experiences using technology in a health context, and more specifically your view on the feasibility of using a tyze network within your daily work at [agency 1]. We want your help to understand some of the potential barriers and opportunities you would expect in the use of this technology. This conversation will take place either as an individual interview, or group focus group, which will be scheduled at a convenient location and/or time for you. The conversation will be led either in-person or over the telephone by one or more of the researchers and will last for up to one hour.

After you share your opinions with us in a focus group or interview, we will ask if you are interested in learning how you can help us answer our second research question, by helping to connect one or more [agency 1] client with their own tyze network. This choice is completely voluntary, and by no means are you obligated to be part of a network by participating in the engagement session.

What are the Risks and Discomforts?

We do not think there will be any risks or discomfort from your participation in the research.

What are the benefits of the research and benefits to you? No one knows whether or not you will benefit from this study. There may or may not be direct benefits to you from taking part in this study.

Voluntary Participation: Your participation in the study is completely voluntary and you may choose to stop participating at any time. Your decision whether or not to participate has no effect on your employment with [agency 1] now or in the future. You can decline to participate in the study without penalty. If you agree to participate, you will be able to talk about whatever you are comfortable with. If there is an interview question you don't want to answer, you would just say something like, 'I don't want to answer that question.'

Withdrawal from the Study: You can stop participating in the study at any time, for any reason, if you so decide. Your decision to stop participating, or to refuse to answer particular questions, has no effect on your employment with [agency 1] now or in the future. If you decide to leave the study, all of the data collected from you will be immediately destroyed wherever possible.

Confidentiality: All information you give during the research will be held in confidence. Your data will be kept in a locked filing cabinet at the [agency 1] Research Unit, and will be accessible only by the members of the research team. Your name will not appear on any data. Only the project team will have access to entire interviews. We might use parts (clips) of your interview in the following ways:

- in teaching and demonstration materials,
- in scholarly papers, articles and other publications, and
- In presentations at academic, health care conferences.

Confidentiality will be provided to the fullest extent possible by law.

Questions about the Research? If you have questions about the research in general or about your role in the study, please feel free to contact Dr. Kerry Byrne either by telephone at (604) 628 9594 or by e-mail (kerry@tyze.com).

This research has been reviewed and approved by the York Central Hospital's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process or about your rights as a participant in the study, please contact the research coordinator for the York Central Hospital Research Ethics Board. His name and contact are as follows:

Abel Cheng, York Central Hospital, 10 Trench St., Richmond Hill, ON, L4C 4Z3

Email: acheng@yorkcentral.on.ca or Telephone: 905-883-1212 ext 7569

Conclusion

We are excited about this study and look forward to gaining your insight on Tyze personal networks. We sincerely hope that you will consider participating.

Please review the following statements:

- I have read and understood the participant information and consent form.
- I have had sufficient time to consider the information provided and to ask for advice if necessary.
- I have had the opportunity to ask questions and have had satisfactory responses to my questions.
- I understand that all of the information collected will be kept confidential
- I understand that my participation in this study is voluntary and that I am completely free to refuse to participate or to withdraw from this study at any time without changing in any way the quality of care that my relative receives.
- I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- I understand that there is no guarantee that this study will provide any benefits to me.
- I have read this form and I freely consent to participate in this study.
- I understand that the participant engagement session and interview will be recorded.
- I have been told that I will receive a dated and signed copy of this form

Please indicate your position at [agency 1]:

Please check all that apply:

- I freely consent to participate in the following...
- Verbal information session/ online demonstration
- Focus group
- Individual interview

My signature below indicates my consent.

Signatures

Printed Name of Participant	Signature	Date
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Printed Name of Principal Investigator/ Designated representative	Signature	Date
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Signature of Participant	Date
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When this study is completed, we will write up a summary of the results. Would you be interested in receiving a copy?

- Yes, please email me a summary of results. My email address is:
- Yes, please mail me a summary of results. My mailing address is:
- No, I do not wish to receive a summary of results