

Perspectives of People Living With HIV:
Activity and Participation Needs When Living at a Distance from Specialized Services

by

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Abstract

The needs of people living with HIV in Manitoba, who reside outside of Winnipeg, are not specifically known. There is evidence of health disparity in North America for people living with HIV at a distance from specialized HIV services when compared to those living in larger metropolitan centres. A better understanding of needs in context is required to address health inequities. Although life expectancy has improved for people living with HIV who have access to treatment, HIV results in challenges related to long-term effects of HIV infection, aging with a chronic health condition, and treatment consequences. Rehabilitation therapies can facilitate people living with HIV to achieve self-identified goals related to living and aging well, but may be difficult to access for those people living with HIV at a distance. The purpose of this study was to examine the needs of adults living with HIV outside of Winnipeg in Manitoba, and use the findings to guide recommendations that address identified needs when living at a distance from specialized services. A mixed-methods, embedded concurrent study design was used. Adults living with HIV in rural areas of Manitoba were purposefully selected through a provincial HIV program. Each participant completed a qualitative semi-structured interview exploring resources, barriers and needs related to participating in daily activities. Participants then identified high priority needs and completed three questionnaires: the Patient Activation Measure® (PAM-13®); questions about access and use of telephone and Internet, including questions adapted from the Unified Theory of Acceptance and Use of Technology 2 (UTAUT2); and a demographics and history questionnaire. Questionnaire data were analysed to describe participants' characteristics. Interview transcripts were analysed using an interpretive description approach and content analysis to produce themes of identified needs. Qualitatively derived needs were merged with descriptive characteristics in joint display to identify patterns of needs among

participants. Seventeen adults with diverse demographic characteristics prioritized nine common needs in three key areas: essential needs for living with HIV, unmet needs, and needs related to combating stigma. Internet access and use was common ($n = 14$), but still inaccessible for some participants with low income and no experience. Joint display tables illustrate patterns of participant reported needs based on gender, age, recruitment site, and other characteristics.

Participants with diverse characteristics shared the need for access to peer support.

Understanding the needs of people living with HIV at a distance from services may help improve experiences of health disparity and disability. Action is needed to address identified needs at clinical, research and policy levels. The UTAUT2 can guide the development of using telephone and Internet to augment access to services at a distance. Community based approaches and the greater involvement of people living with HIV at all levels of intervention is indicated, and should include capacity building and remuneration.

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Chapter 1: Introduction

In 2016, Manitoba had the second highest rate of newly reported positive human immunodeficiency virus (HIV) cases in Canada (Bourgeois et al., 2017). The Manitoba HIV Program provides specialized health services to approximately 1,285 adults living with HIV (Manitoba HIV Program, 2017). Although only 18% of new clients lived outside of the Winnipeg Regional Health Authority in 2016 (Manitoba HIV Program, 2017), this number has been as high as 34% in 2013 (Government of Manitoba et al., 2014), and 24% in 2015 (Manitoba HIV Program, 2016).

The rehabilitation needs of people living with HIV in Manitoba, who reside outside of Winnipeg, are not specifically known. HIV treatment in Manitoba is Winnipeg-based, requiring people living with HIV residing elsewhere in the province, to travel to Winnipeg for HIV care. Rehabilitation has been identified as “critical to helping [people living with HIV] achieve optimal health” (Canadian Working Group on HIV and Rehabilitation, 2015, p. 33). However, rehabilitation specialists who work with people living with HIV are few and, similar to medical specialists, are typically located in urban centres (Worthington, O’Brien, Myers, Nixon, & Cockerill, 2009).

Limited access to HIV services is a challenge for people living outside of Winnipeg, who tend to present to care with more advanced HIV illness (Manitoba HIV Program, 2015). Barriers to receiving HIV services in rural areas, or areas at a distance from where specialized services are provided, include transportation, provider discrimination, stigma, affordability and concerns about confidentiality, and result in health disparity for this population (Pellowski, 2013; Rapid Response Service, 2013a).

Information and communication technologies (ICT) have been identified as a means to provide HIV services in rural areas by facilitating access to health information and professionals who are knowledgeable about HIV (Rapid Response Service, 2013a; Veinot, Harris, Bella, & Challacombe, 2010), but others suggest that access and use of ICTs may be limited in rural settings (Haight, Quan-Haase, & Corbett, 2014; Melvin, Bunt, Oduor, & Neustaedter, 2015).

The principal investigator conducted a mixed methods needs assessment of adults living with HIV outside of Winnipeg, Manitoba. The primary strand of the study was qualitative, used an interpretive description approach (Thorne, 2016), and guided the study design. The secondary strand of the study was quantitative, and supported the findings with descriptive context. Joint display of qualitative themes and descriptive quantitative data illustrated typical participant characteristics associated with common participant needs. A three phase, systematic approach was applied to the study design, as described by Witkin and Altschuld (1995), and used a pragmatic, transformative perspective (Creswell, 2014) to understand the needs of adults living with HIV at a distance from specialized services in Manitoba.

Principal Investigator's Context

Although qualitative interpretive description does not prescribe to any one theoretical framework, it was founded on constructivist assumptions, including that the researcher's perspective and experiences shape an unavoidable interpretation of the data when seeking to understand context to guide discipline specific practice (Thorne, 2016; Thorne, Reimer Kirkham, & MacDonald-Emes, 1997; Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). Creswell (2014) recommends that researchers make their *worldview*, or “general philosophical orientation about the world and the nature of research that a researcher brings to a study” (p. 6) known. In this case, the principal investigator is a graduate student with previous clinical experience as an

occupational therapist for 12 years at the time of this study's initiation. The principal investigator has lived and worked in Manitoba for over 13 years, with five years of clinical experience while living in remote Northern Canada. Previous research experience includes working on both quantitative and qualitative studies with participants of all ages and includes research with people living with episodic health conditions including HIV. Clinical work experiences have contributed to the principal investigator's desire to conduct research that leads to change for people who strive to meet self-identified health goals, and solves real-world problems faced in daily practice. Through practice experience in remote areas, the principal investigator developed an understanding of the complexity of living with chronic health conditions that require specialist care, and the need for an interdisciplinary approach. The principal investigator's supervisor is also an occupational therapist, and the thesis committee includes representation from occupational therapy, medicine and nursing disciplines.

Chapter 2: Review of Literature

The purpose of this literature review is multifold and aimed to: provide current background information about living with HIV in a rural context; define and introduce a medical rehabilitation framework and context that relates to the principal investigator's discipline; and identify current literature and methods for determining the needs of people living with HIV in rural areas. Additionally, this review aimed to identify gaps in the literature related to the activity and participation needs of people living with HIV in non-metropolitan areas of Manitoba, and justify this study's purpose and design. Specifically, current literature regarding living with HIV in the era following the advent of highly active antiretroviral therapy (HAART) will be reviewed. Rehabilitation for people with HIV will be defined and a relevant framework will be described. Self-management of HIV in the context of living with a chronic condition and the role

of individual activation will be considered. What is known and what is missing in the literature regarding living with HIV in rural Canada will be outlined, including access and use of personal telephone and Internet technology to attain rehabilitation goals. Evidence specific to the context of living with HIV in non-metropolitan areas of Manitoba will be described, followed by the research problem addressed by this study, and literature regarding methodology for addressing complex issues. Finally, this section will end by stating this study's purpose and research objectives.

Living with HIV in the Post HAART Era

Due to advancements in HAART, HIV is now considered a chronic, episodic condition with unpredictable and fluctuating periods of illness and wellness (Canadian Working Group on HIV and Rehabilitation, 2015; World Health Organization, 2002a). HAART is not a cure, but manages viral load in the body, allowing the immune system to recover from ongoing attacks by the virus. Treatment success is dependent on lifelong adherence to a daily pharmacotherapy regime, and is acknowledged as a complex phenomenon (Penn, Watermeyer, & Evans, 2011). Maintaining a healthy lifestyle routine in activities of daily living is one contributing factor to improving HAART adherence (Penn et al., 2011). HAART allows people living with HIV to live longer, but can result in physical, cognitive, social and emotional challenges related to the long-term effects of HIV infection, aging with a chronic health condition, and treatment consequences (Canadian Working Group on HIV and Rehabilitation, 2015; Rusch et al., 2004). Rusch et al. (2004) conducted a cross-sectional population based survey to establish prevalence of disability in people living with HIV in British Columbia, Canada. The anonymous survey had a 50% response rate from participant members of a non-profit society for people living with HIV. Participants reported high prevalence of activity limitation (80%) and participation restriction

(93%). Members of the non-profit society who did not respond to, or were excluded from the survey due to missing data, were reported to more likely be female and Indigenous. The limited response from women and Indigenous people was a limitation of the study, and suggests the possibility that these high rates of disability may be underestimated based on known risk factors and disparity experienced by some people with these characteristics in Canada (Government of Canada & Public Health Agency of Canada, 2006a; Rusch et al., 2004). For example, women are at risk for health disparity related to socio-economic factors and increased risk for sexual violence and HIV related stigma (Public Health Agency of Canada, 2014). Also, Indigenous people are disproportionately affected by HIV in Manitoba (Manitoba HIV Program, 2017), suggesting that other socio-economic factors may contribute to an increased risk of HIV infection.

Another complicating factor in addressing the needs of people living with HIV is rooted in the nature of the virus attacking the immune system and potentially affecting any and multiple systems of the body. Compounded by social factors, like culture, stigma and socio-economic status, that vary across individuals and geographic regions, the needs of people living with HIV are likely to vary (Penn et al., 2011). In a recent scoping review of self-management interventions for people living with HIV, the authors noted the importance of flexible content and service delivery in order to address the diversity of needs (Bernardin, Toews, Restall, & Vuongphan, 2013). The experience of living with HIV is unique and variable based on complex factors including context, posing a challenge to rehabilitation program development.

Rehabilitation for People Living with HIV

Rehabilitation has been defined as “a dynamic process, including all prevention and/or treatment activities and/or services that address body impairments, activity limitations and

participation restrictions for an individual” (Worthington, Myers, O’Brien, Nixon, & Cockerill, 2005, p. 268). As with other chronic conditions, people living with HIV have benefitted from rehabilitation in a variety of settings, such as hospital, primary care and community (Canadian Working Group on HIV and Rehabilitation, 2015; Lapointe, James, & Craik, 2013; Tran, Thomas, Cameron, & Bone, 2007). Rehabilitation can support self-management of chronic health conditions, health promotion and prevention to improve quality of life for people living with HIV and mitigate health costs associated with poorly managed, advanced illness (Canadian Working Group on HIV and Rehabilitation, 2015; World Health Organization, 2002a).

Researchers in consultation with specialists and people living with HIV, support the idea that rehabilitation for people living with HIV should be flexible in content, goal setting and method of service delivery, as well as guided by the goals and priorities of the person living with HIV (Bernardin et al., 2013; Worthington et al., 2005). Occupational therapy is one rehabilitation profession that has been identified as well suited to facilitate activity and participation goals identified by people living with HIV (Bernardin et al., 2013; Canadian Working Group on HIV and Rehabilitation, 2015; Lapointe et al., 2013). Occupational therapy is an evidence based health profession that aims to enable people to participate in self-identified meaningful activities of daily life (Canadian Association of Occupational Therapists, 2007).

Worthington et al. (2005) developed a framework for rehabilitation of HIV/AIDS, drawing from experiences of, and in consultation with, people living with HIV and key informants. The conceptual rehabilitation framework drew upon the World Health Organization International Classification of Functioning (ICF), Disability and Health (World Health Organization, 2002b; Worthington et al., 2005). The focus of the ICF model of disability is on health and function in society and daily life, and recognizes a person’s health condition as

complex, involving personal, medical and social perspectives of function. The ICF model depicts health condition as a result of a combination of factors included in the model: body function, body structures, and impairment; activity and limitations; participation and restrictions; and environmental and personal factors (World Health Organization, 2002b). O'Brien, Bayoumi, Strike, Young, and Davis (2008) updated the concept of disability in the model based on focus groups with 38 adults living with HIV. The “Episodic Disability Framework” consists of three components: dimensions of episodic disability, contextual factors, and triggers. Four dimensions of disability are included in the model: *Symptoms/impairments, difficulties with day-to-day activities, challenges to social inclusion and uncertainty* (O'Brien et al., 2008, p. 81). The second part of the model situates rehabilitation in the context of the person, activities, and their environment, and is categorized as intrinsic (*living strategies or personal attributes*) or extrinsic (*social support or stigma*) factors. The final component consists of triggers related to episodes of disability, for example, receiving a diagnosis of HIV or suffering the loss of others (O'Brien et al., 2008). The purpose of the Episodic Disability Framework (EDF) is multifold and includes: clinical assessment of disability; a guide for clients to communicate barriers to health related goals to their health providers; research; and policy development (O'Brien, Hanna, et al., 2014). O'Brien, Hanna, et al. (2014) found the framework to have construct validity using confirmatory factor analyses on data collected from a cohort study of 913 adults living with HIV. Cohort participants completed a detailed questionnaire that used multiple measures to assess: HIV symptoms, symptoms of depression, health status, health-related quality of life, cognitive function, housing, employment, education, income, and occupation. Questionnaire items were matched with each dimension of disability in the Episodic Disability Framework, except for the dimension of *uncertainty*, as none of the instruments administered to the cohort measured

uncertainty. Some limitations of the study were: limited variability of a predominantly White male sample; all participants were from the Greater Toronto Area in Ontario; and the dimension of uncertainty was not included in the analysis as it was not assessed by any of the measures collected from the cohort participants (O'Brien, Hanna, et al., 2014).

Self-Management of HIV and Activation

Although rehabilitation can facilitate people living with HIV to manage their daily health (Canadian Working Group on HIV and Rehabilitation, 2015), it is hypothesized that a person's success with managing a chronic health condition is associated with their individual level of activation (Greene, Hibbard, Sacks, Overton, & Parrotta, 2015; Hibbard, Mahoney, Stock, & Tusler, 2007). Hibbard, Stockard, Mahoney, and Tusler (2004) define activation as the self-perceived knowledge, skill, and confidence an individual has in managing their chronic condition, and includes perceiving themselves as active in their own care. Activation is theorized to develop in four stages of lower activation to higher activation, ranging from (a) perceiving an active role in one's own health is important, (b) having sufficient information and skill to act in the interest of one's own health, (c) making changes in lifestyle to improve health, and (d) maintaining a healthy lifestyle even in times of stress (Hibbard et al., 2004). Studies show that activation level can be modified and that higher levels of activation are associated with improvement in self-management behaviour such as participating in regular exercise and stress management (Hibbard et al., 2007). With the goal of developing a measure that identifies a person's level of activation, Hibbard, et al. (2004) developed the Patient Activation Measure® (PAM®). Identifying people with lower activation levels using the PAM may identify people most at risk for poorly managed chronic conditions and allow development of targeted intervention for those most in need, leading to efficient use of limited resources (Hibbard,

Greene, & Tusler, 2009). Appendix A outlines further information about the PAM-13 and licensure for use in this study.

Living with HIV in Rural Areas

Despite the evidence that rehabilitation services are well matched for meeting needs of people living with HIV, HIV rehabilitation services are predominantly located in urban centres (Worthington et al., 2009). In addition to disparity of access to HIV rehabilitation services based on rural living, disparity in health status of rural versus urban populations in Canada is recognized (Aoki, Dunn, Johnson-Throop, & Turley, 2003; DesMeules et al., 2011; Laurent, 2002). It is estimated that there were approximately 68,800 people living with HIV in Canada in 2011 (Public Health Agency of Canada, 2015). It is not known how many people were living with HIV in rural areas of Canada in 2011. Based on knowing that 19% of the population lived in rural areas at that time, it can be estimated that there were approximately 13,100 people living with HIV in rural areas of Canada at the end of 2011 (Public Health Agency of Canada, 2015). This may be an overestimate given there is some evidence that people living with HIV may leave rural areas to access HIV health services and supports, among other reasons (Groft & Robinson Vollman, 2007; McCall, Browne, & Reimer-Kirkham, 2009; Veinot et al., 2010). The lack of data related to the prevalence of HIV in rural Canada is an indication of the gap of knowledge in this area. Evidence supports that people living with HIV in rural Canada experience additional barriers to accessing health services compared to urban counterparts (Groft & Robinson Vollman, 2007; Veinot & Harris, 2011; Veinot et al., 2010), resulting in health disparity for this specific population (Rapid Response Service, 2013a). Specialized services have always been difficult to provide to small numbers of people living in low populated areas, separated by large geographic distance. A recent summary of evidence regarding HIV services in rural

communities, outlined known barriers (Rapid Response Service, 2013a). Lack of health services, including skilled HIV services and professionals, transportation issues, geographic and social isolation, stigma, and lack of trust in confidentiality of health services, are all identified as challenges for people living with HIV in a rural versus urban environment (Rapid Response Service, 2013a). Additionally, men who have sex with men, and women with HIV living in rural areas have been found to experience higher levels of discrimination, violence and social isolation (Rapid Response Service, 2013a). These factors, in addition to barriers preventing access to health services, can lead to higher potential for disability (Gonzalez, Miller, Solomon, Bunn, & Cassidy, 2009; Williams, Bowen, & Horvath, 2005).

Despite an understanding of barriers to accessing health and HIV services in rural Canada, the rehabilitation needs of people living with HIV in rural Canada are largely unknown. Limited information is available in the literature regarding what it is like for people living with HIV in rural Canada. Groft and Robinson Vollman (2007) interviewed seven people with the goal of exploring living with HIV in rural Western Canada. Participants perceived challenges unique to living in a rural context consistent with the literature, such as difficulty accessing services, lack of services or trained personnel, cost of accessing services, social isolation and concerns about stigma and lack of trust in confidentiality when seeking and using services related to HIV in their community (Groft & Robinson Vollman, 2007). Although McCall, Browne and Reimer-Kirkham (2009) interviewed urban living Indigenous women, seven out of eight participants were originally from rural areas. Their findings noted similar challenges for rural living participants, including feeling forced to relocate to urban areas in order to access specialized HIV services, often leaving behind affordable living options and social support (McCall et al., 2009).

Veinot et al. (2010) identified differences in access to information about HIV between rural and urban living people in Canada. People living in three rural communities were surveyed and found to be less knowledgeable about HIV compared to people living in urban areas (Veinot & Harris, 2011). American researchers have noted that people living with HIV in rural areas are more likely to be diagnosed later, with more advanced disease, are less likely to have access to new treatments, and are less likely to be taking HAART (Ohl et al., 2013; Trepka et al., 2014). None of the studies reviewed involved people living with HIV prioritizing their rehabilitation needs within a context of living in rural Canada.

The complexity of assessing needs of people living in rural areas was acknowledged by Dal Bello-Haasm, Crammer, Stewart and Kosteniuk (2014). Mamary et al. (2004) highlight the importance of involving service recipients and applying multi-method approaches when assessing needs in specific geographic and cultural context. An in-depth needs assessment of an HIV care program serving a mostly rural district of Northeast Georgia also applied mixed-methods research in order to identify and prioritize needs of people living with HIV (Huff, Chumbler, Cherry, Hill, & Veguilla, 2015). Some barriers and needs identified by the assessment were similar to existing evidence and included: concerns about privacy when seeking HIV care; lack of trained providers; costs of medications; and stigma experiences in the health care setting. Other barriers were unique to the program, such as poor moderation of support groups and difficulties with referrals for non-HIV related health issues. Recommendations arising from the needs assessment were predominantly geared towards reducing barriers to care for service users in rural areas and included: health care outreach services to remove geographic barriers; improvement of physical spaces to increase privacy; use of technology to improve access to care; and targeted education outreach in rural communities (Huff et al., 2015).

Information and Communication Technology for Augmenting Access to Rehabilitation**Services for HIV Management in Rural Areas**

Information and communication technologies (ICTs) have been identified as a best practice to improve access to health services for people living with HIV in rural areas (Giliauskas, Mitra, Globerman, & Bacon, 2015). ICTs include any technology used to communicate and process information (Zhang & Li, 2017), of which some examples include telephones (e.g., landline, cellular, smartphone, and mobile devices), the Internet, wireless and wired networks, computer based devices, and more. Some examples of ICTs applied to augment access to health care services in rural areas include: telehealth from local health centres for consulting with specialists in urban centres; using the telephone for therapeutic and support services; and using the Internet for education, peer and professional support (Rapid Response Service, 2013a). Given the barriers outlined for people living with HIV in rural areas, literature reviewed focused on client-centred, tailored interventions that are accessible by commonly found ICTs accessed by individuals in rural Manitoba. Although the quality of communication may vary based on specific location infrastructure and weather, landline telephones, cellular phones and Internet applications are common modes of communication (Melvin et al., 2015). Focus also narrowed on interventions addressing tailored rehabilitation management of HIV or other chronic health conditions. Occupational therapy has been delivered using ICT to facilitate self-management of other episodic and chronic health conditions. Finlayson, Preissner, Cho, and Plow (2011) found a treatment delivered by group teleconference for people with Multiple Sclerosis to be effective at reducing the impact of fatigue. Another study trialing occupational therapy by telephone sessions to rural breast cancer survivors reported that 92% of participants found the service helpful in overcoming participation restrictions (Hegel et al., 2011).

Videoconferencing using the Internet has also been used to provide occupational therapy services to a client at home, from a distance, for cognitive rehabilitation (Ng, Polatajko, Marziali, Hunt, & Dawson, 2013), and to improve oral health and independence with self-care despite tetraplegia (Yuen, 2013).

Despite the promise of using ICTs such as landline telephones, cellular phones, and the Internet to improve access to rehabilitation services for people living at a distance from in-person services, some researchers report that people living with HIV in rural areas may lack access to, skill with, or interest in the Internet, adding another barrier that contributes to health disparity. For example, R. M. Harris, Wathen, and Fear (2006) surveyed a random sample of 253 people by phone in rural Ontario. Forty-one per cent of respondents looking for health information did not use the Internet, and about 66% of these respondents reported no, or limited access to, the Internet where they live (R. M. Harris et al., 2006). A needs assessment in rural northern California included focus groups with people living with HIV regarding delivery of HIV primary care services in the region. At that time, rural participants “emphatically rejected e-mail” mostly because they did not own computers (Mamary et al., 2004, p. 162). More recently, an analysis of factors affecting Internet use in Canada, based on population based sample data from 2010, show a persistent urban-rural digital divide, in which urban dwellers were 51% more likely to access the Internet compared to rural dwellers, when controlling for factors of income, education, gender, immigration status and age (Haight et al., 2014). Additionally, people living in rural areas who had Internet access were found to have lower online activity compared to people living in urban locations (Haight et al., 2014). This urban-rural digital divide may be underestimated due to the survey data not including people living in the territories, nor people living on First Nations reserves (Haight et al., 2014). Differences in the quality of Internet access

are also context dependent. Despite media reports of improvements to Internet access in rural Manitoba (James, 2012), as of 2016, Manitobans were reported to have the second slowest Internet speeds in Canada (Canadian Internet Registration Authority, 2016). Although a January 9, 2018 news release announced funding to bring high-speed Internet infrastructure to 72 rural and remote communities in Manitoba (Province of Manitoba, 2018), connectivity challenges are noted in both southern and northern rural areas of the province (Melvin et al., 2015). In summary, use of ICT depends on specific geographic, personal, social, and cultural factors, and cannot be assumed for any individual.

Models explaining adoption and use of services delivered using ICT also demonstrate the complexity of context dependent methods and draw from multiple disciplines. For example, the Unified Theory of Acceptance and Use of Technology (UTAUT) is a multidisciplinary model for predicting intention to use, and use of, a new technology (Venkatesh, Morris, Davis, & Davis, 2003). The model was derived from eight popular models and was found to explain 70% of the variance in an individual's intention to use a new technology. The resulting model found performance expectancy (perceived benefits of the technology), effort expectancy (how easy the technology is to use), social influence (perceived importance of the technology to others), and facilitating conditions (perceived resources and supports for using a technology) to be independent predictors of behavioral intention and use; however these variables were moderated by gender, age, experience, and whether or not the technology in question was voluntary or mandated (Venkatesh et al., 2003). Van Dijk, Peters, and Ebbers (2008) chose the UTAUT as the basis of a modified multidisciplinary model to use structural equation modeling in a population based survey that aimed to explain acceptance and use of government Internet services in the Netherlands. Internet service supply, digital media access, experience and preference, knowledge

of services, and effort expectancy were found to be causal factors explaining intention and actual use of government delivered Internet services (van Dijk et al., 2008). The UTAUT model was extended to examine acceptance and use of a new technology in a customer service context and is called the UTAUT2. The UTAUT2 assumes the technology in question is being used voluntarily in a consumer context, and adds three additional constructs to the model: hedonic motivation (how fun it is to use the technology), price value (perceived value given the cost of the technology), and habit (perceived routine use of the technology; Venkatesh, Thong, & Xu, 2012). Given the ongoing trends in patient-centred care (Canadian Medical Association & Canadian Nurses Association, 2011), a consumer model like the UTAUT2 for predicting intention and personal use of the Internet for accessing health interventions may be the best fit for assessing an individual's likelihood of adopting the use of personal ICTs at home to access electronic health (eHealth) or mobile health (mHealth) applications. Testing of the UTAUT2 explained 74% of the variance in an individual's intention to use purchased mobile Internet technology. Venkatesh et al. (2012) found that user characteristics of age, gender and experience moderated the UTAUT2 factors, and that this information may help guide the design of applications to improve uptake and use. For example, Venkatesh et al. (2012) found that external supports are more critical for older women, and older adults in general in the beginning stages of using a new technology, whereas younger men, and men in general may be more motivated by how fun the application is early on in adoption. They also found that older men may need designed intervention if the use of the technology requires a change in their habits (Venkatesh et al., 2012). Venkatesh et al. (2012) acknowledge that these moderating characteristics may vary among different cultures, and requires further study among different populations, technologies and contexts.

A literature search for an assessment tool regarding an individual user's readiness for using existing, personally owned ICTs to access health related services reflected an absence of literature. Few located references focused on assessing an individual's readiness independent of local health practitioners and services. Jennett et al. (2003) developed a *Patient/Public Telehealth Readiness Assessment Tool* from interviews, focus groups and consultation with patients, practitioners and health organizations in a Canadian rural community. The tool assessed Telehealth readiness with a 6-point Likert scale on 17 items in three areas: core readiness, engagement readiness, and structural readiness. However, structural readiness items require established connection with local health providers, community equipment and organizations; all of which were found to be potential barriers to people living with HIV in rural areas (Rapid Response Service, 2013a). The Jennett et al. (2003) tool is intended to be used together with assessment of a local organization and practitioner readiness tools, and does not assess the patient's independence with accessing and using ICTs from home.

The Patient eHealth Readiness Questionnaire (PERQ) was developed to assess an individual's opportunity, skills, financial and social supports to use the Internet in various formats to improve health, and was designed to assess both Internet and non-Internet users (Jones, 2013). However, this tool was developed and validated only with a British population, and uses terms that are not culturally relevant in Manitoba. The Canadian Internet Use Survey is a 55-item questionnaire that assessed individual use of high-speed Internet resources (Statistics Canada, 2012). One purpose of the survey was to determine underserved areas and where to extend higher quality Internet services in Canada (Statistics Canada, 2012). However, the closed ended survey format regarding technical access and use does not capture potential barriers or reasons for lack of adoption of technology related to socio-cultural context. To understand the

barriers and resources related to personal access and use of common ICTs, whether or not a person has access to telephone and Internet must be established (Jones, 2013; van Dijk et al., 2008). Additional, more complex factors also need to be explored, such as personal values and knowledge, cultural attitudes and social supports around personal ICT access and use prior to developing tailored rehabilitation applications that can be accessed at a distance (Suarez-Balcazar, Balcazar, & Taylor-Ritzler, 2009; Venkatesh et al., 2012).

Context of the Study

Given the importance of geographic and social context noted in the literature, this section will summarize the specific context of this research. This study took place in Manitoba, Canada. Current existing literature about people living with HIV who reside in Manitoba, but outside of Winnipeg, is summarized. Research methodology to address complex problems is discussed in light of the study research problem. A rationale for needs assessment methodology will be presented, leading to the purpose of this thesis.

People living with HIV in rural Manitoba. The needs of people with HIV living outside of Winnipeg, the sole metropolitan centre in Manitoba where specialized HIV services are based, are not specifically known. It is estimated that 2,100 Manitobans are living with HIV. In 2013, 34% of people newly diagnosed with HIV were living in regions outside of Winnipeg (Government of Manitoba et al., 2014). Compared to previous years, this was noted as a possible “apparent shift” (p. 13) in seeing more cases identified outside of Manitoba’s largest urban center of Winnipeg (Government of Manitoba et al., 2014). In 2016, 18% of new clients were living outside of the Winnipeg Regional Health Authority (Manitoba HIV Program, 2017). Since 2015, the Manitoba HIV Program has reported that new clients presenting for care who were living outside of Winnipeg, were more likely to be later in the course of HIV infection (Manitoba

HIV Program, 2015, 2016, 2017). Late presentation to care is associated with more severe illness and increased risk of transmitting HIV to others (Manitoba HIV Program, 2015). The Manitoba HIV Program (2015) also notes a lack of HIV services in rural and remote areas of Manitoba as a barrier to care for people living with HIV outside of Winnipeg.

Manitoba Health's most recent report summarizes that province wide, 69% of new cases in 2016 were male, 39% self-reported as Indigenous, 31% African/Caribbean/Black, and 23% Caucasian. The three main self-reported risk exposure categories of people newly diagnosed with HIV in Manitoba were: (a) heterosexual contact, 56%; (b) men who have sex with men, 25%; and (c) intravenous drug use, 11% (Manitoba HIV Program, 2017). This description is notably different from the sample that responded to Rusch's et al. (2004) impairment prevalence study in British Columbia where respondents self-reported as being 89% White, 77% sexual minority males. This suggests impairment and needs of people living with HIV may differ between Canadian provinces or regions based on the varied transmission dynamics and demographics of people living with HIV.

Although roughly only a fifth of people newly diagnosed with HIV in Manitoba in the last four years reported living in rural areas, there is evidence that those with HIV living in rural areas may face even more complex barriers to health and health services than urban counterparts (Groft & Robinson Vollman, 2007; Manitoba HIV Program, 2017; Rapid Response Service, 2013a; Zukoski, Thorburn, & Stroud, 2011). The actual number of people living with HIV in rural Manitoba is not known. People living with HIV in rural areas report more stress, less life satisfaction, poorer coping strategies and reduced social support compared to people living with HIV in urban areas (Rapid Response Service, 2013a). The literature indicates region-specific challenges related to geography and culture that require tailored consideration in order to reduce

this health disparity (DesMeules et al., 2011; Rapid Response Service, 2013a; Sullivan-Bolyai, Bova, & Harper, 2005).

Research for change: addressing complex problems. As previously noted, HIV results in a wide range of physical, psychological and social impairments, that is understood to be helped or hindered by an individual's environmental factors or context (O'Brien et al., 2008). Due to the variety of impairments, interaction of factors affecting health, and diversity of needs and goals of people living with HIV identified in the literature, flexible and tailored interventions are required (Bernardin et al., 2013). The Manitoba HIV Program also notes that provincial transmission dynamics are variable from year to year, requiring care approaches that are responsive to changes in needs (2016). Additionally, fewer people live in rural areas compared to urban centres, and are separated by significant distance from existing services. These factors combined result in the need for relatively complex intervention (Craig et al., 2008) for people living with HIV outside of Winnipeg, in Manitoba.

The Research Problem

The rehabilitation needs, resources and barriers to daily activity and participation of people living with HIV outside of Winnipeg, in Manitoba are not known. Although people living with HIV outside of Winnipeg make up approximately 30% of people known to be living with HIV in Manitoba (Government of Manitoba et al., 2014), this population is likely to experience increased risk related to limited resources, economic disadvantage, late diagnosis and complex health and social issues (Gonzalez et al., 2009; Manitoba HIV Program, 2017; Ohl et al., 2013; Pellowski, 2013; Veinot & Harris, 2011). Needs assessments conducted with specific, disadvantaged populations, like people living with HIV in rural areas, are important because potential costly health disparities in a complex environment of culture, social norms and

geographic context, need to be understood in order to develop effective solutions (Huff et al., 2015; Sullivan-Bolyai et al., 2005). For people living with HIV in Manitoba, at a distance from HIV specialized services, the literature identifies the potential for high-risk health needs and differences according to geographic, social and cultural context (Government of Manitoba et al., 2014; Groft & Robinson Vollman, 2007; Rapid Response Service, 2013a).

Prior to developing an effective intervention with the aim of improving activity engagement and participation for adults living with HIV outside of Winnipeg, in Manitoba, a clear understanding of the problem is imperative. If the needs of a group are not understood well enough to be identified, quantified and prioritized, preliminary research is required (Campbell et al., 2007). Campbell et al. note that “qualitative research can explore opportunities for, and barriers to, change” (2007, p. 457). A mix of methods is often suggested for fully understanding a complex health problem, and includes gathering qualitative and quantitative data, integrating demographics and key health condition related statistics (Wilkinson & Murray, 1998), to complement, compare or guide other sources of information (Creswell, 2014; Wilkinson & Murray, 1998). This project contributed to developing a clearer understanding of needs and priorities of adults living in Manitoba, but outside of Winnipeg, as the first step in planning intervention strategies for this population.

Needs Assessment Methodology

Witkin and Altschuld define needs assessment as: “A systematic set of procedures undertaken for the purpose of setting priorities and making decisions about program or organizational improvement and allocation of resources. The priorities are based on identified needs” (1995, p. 4). Well-designed needs assessments ideally result in identification of high risk needs, and result in action to meet the needs of service recipients (Witkin & Altschuld, 1995). A

needs assessment may lead to matching the needs of a defined population with suitable services, and serve to reduce health disparity and barriers to services. By considering data from multiple sources on an issue, “what should be done, what can be done, and what can be afforded”, can be considered as a whole to develop the best possible solution in the context of the problem (Wright, Williams, & Wilkinson, 1998). There is no one way to conduct a needs assessment; rather, a needs assessment will require different methods, depending on the purpose, target population and context of the identified problem (Witkin & Altschuld, 1995; Wright et al., 1998).

Witkin and Altschuld (1995) describe a three-phase framework for designing and conducting needs assessments. In the first phase, preassessment, purpose, objectives and methods are determined. The second phase, assessment, involves collecting, analysing and interpreting data from methods identified in phase one. Finally, the last phase is postassessment, where the results are used to develop, implement, and evaluate the needs assessment and outcomes (Witkin & Altschuld, 1995).

Purpose

The purpose of this study was to conduct the assessment phase of a needs assessment involving adults living with HIV outside of Winnipeg, in Manitoba. This study identified, described, and prioritized the rehabilitation needs of participants from their perspective, and described perceived barriers, resources and solutions to meeting needs, including personal access and use of telephone and Internet. Qualitative interview data and quantitative survey data described participants and their needs in the environmental context of living in non-metropolitan areas of Manitoba.

Research Objectives

An important and feasible first step in a needs assessment is the pre-assessment of objectives and methods of the needs assessment, and the assessment of needs of the service recipients (Witkin & Altschuld, 1995). The purpose of this study was to conduct the assessment phase of a needs assessment with people living with HIV outside of Winnipeg, in Manitoba. The preassessment phase of determining objectives and methods was determined from prior evidence and gaps reported in the literature.

Quantitative research objectives, secondary strand. The quantitative aim of this study was to:

1. Create a descriptive synopsis of participants' characteristics to complement understanding of participants' needs in context. Results describe participant characteristics of age, sex, ethnicity, sexual orientation, history of HIV infection, perceived current health status, personal access and use of telephone and Internet, and patient activation level as determined by the PAM-13.

Qualitative research objectives, primary strand. The qualitative aim of this study was to:

2. Identify, describe and prioritize needs from the perspective of adults living with HIV, outside of Winnipeg, in Manitoba. The description of needs includes participants' perspectives of barriers, resources, and solutions to meet identified needs. Participants' perceptions of resources and barriers to accessing the Internet for personal use were specifically sought to inform ways to improve access to services at a distance in order to address identified needs.

Mixed methods research objectives. The mixed methods aim of this study was to:

3. Identify patterns of prioritized needs based on participants' characteristics. A joint display analysis examines each qualitatively identified need with the associated quantitatively derived descriptive synopsis of the participants who prioritized each need.

Chapter 3: Methods

The research design, procedures, data collection, data management, and data analysis process for this mixed methods study is outlined in this chapter. A detailed section on strategies incorporated to support the trustworthiness of the study results and interpretation is also included. The chapter concludes with ethical and feasibility considerations. Proposed and actual study time lines, and the study budget are in Appendix B and C, respectively.

Research Design

This study used a mixed-methods, embedded concurrent design, and joint display to merge qualitative and quantitative results. The primary strand of the study was qualitative research and guided the study design. The secondary strand was quantitative research with lesser emphasis. The overall study design was guided by transformative and pragmatic worldviews (Creswell, 2014), and acknowledged the constructivist nature of interpretive description (Thorne, 2016). A diagram of the mixed methods study design is in Appendix D, where “QUAL” represents the emphasized primary strand of the study, and “quan” represents the secondary strand, as represented in mixed methods research (Creswell, 2014, pp. 228–229).

Concurrent mixed methods research involves collecting both qualitative and quantitative data and merging the results to develop a more complete understanding of a research problem than either qualitative or quantitative inquiry alone (Creswell, 2014). Although a relatively new research methodology, mixed methods originated in the 1980s and has been adopted by many disciplines in varied fields of research worldwide, including health, education and business

management (Creswell, 2014). Mixed methods have been used to explore complex phenomenon including the needs of people living with HIV in rural areas (Huff et al., 2015; Mamary et al., 2004). Mixed methods, as a research approach, is considered useful in that it benefits from the combined outcomes of both qualitative and quantitative inquiry, resulting in a more thorough understanding of the phenomenon in question (Creswell, 2014). For this study, mixed methods design aimed to understand the detailed participant perspective of unmet needs in context from qualitative in-depth interviews, as well as describing characteristics of participants with summary statistics of demographics, HIV history, access to telephone and Internet technology, and level of activation from quantitative survey data. Joint display was used to merge qualitative needs with quantitative description to illustrate emerging patterns of needs according to demographics, HIV history, access to telephone and Internet, and activation level according to the PAM-13.

In keeping with a needs assessment approach, as described by Witkin and Altschuld (1995), this study aimed to use results to develop recommendations that address the activity and participation needs of adults living with HIV in rural Manitoba.

The following sections will describe and justify the specific methods selected for the secondary quantitative and primary qualitative strand of this mixed methods study.

Quantitative design. Quantitative data were sought to describe characteristics of the sample, and support an aim to more fully understand the contextual experience of participants by mixing qualitative and quantitative data. Quantitative data comprised three participant-report questionnaires administered in the following order: (1) the PAM-13 (Hibbard, Mahoney, Stockard, & Tusler, 2005); (2) access and use of telephone and Internet for personal use questionnaire; and (3) demographics and history questionnaire. The PAM is a licensed, commercial measure of self-reported efficacy, knowledge and skills to manage one's health

(Hibbard et al., 2004). Further details about the PAM and its use in this study are found in Appendix A. The access and use of telephone and Internet for personal use and demographics and history questionnaires are found in Appendices E and F respectively. These two questionnaires were developed for this study to capture descriptive data identified in the literature review as relevant to the context of HIV in Canada, and to understand personal access and use of telephone and Internet. The questionnaires were administered to participants following completion of the qualitative semi-structured interview. Participants completed the interview and questionnaires either by telephone or in person. In order to maintain a consistent method of collecting questionnaire data, the principal investigator read questions to each participant, regardless of interview context, and recorded participants' verbal responses in writing. This approach had the added benefit of facilitating participants with varied levels of literacy and visual function. The principal investigator also explained terms to participants who asked for clarification. The administration of the questionnaires was digitally recorded and responses were checked for accuracy against transcripts by the principal investigator. The following sections provide more detail as to the rationale for collecting specific quantitative data according to each questionnaire.

The PAM. The PAM is a measure of self-reported efficacy, knowledge and skills to manage one's health (Hibbard et al., 2004). The outcome of the PAM is a level of patient activation that can be used as a "summary indicator" that may identify people living with HIV who are at greater risk for poor health outcomes (Marshall et al., 2013, p. 672). It also provides an indication of how to tailor interventions to address different levels of activation, which has been found to improve the success of interventions for people living with HIV (Marshall et al., 2013). The PAM-13 was used in this study to determine if there were any patterns of

characteristics or qualitative themes of needs that aligned with lower, or at-risk levels of activation as determined by PAM score.

The original 22-item PAM was developed using expert consensus and focus groups with people living with chronic disease to generate items, later refined using Rasch methods and a United States national probability sample (Hibbard et al., 2004). The goal of developing the PAM was to empirically conceptualize and measure patient activation as an indicator of a person successfully managing living with chronic health condition (Hibbard et al., 2004). Hibbard et al. (2005) developed and tested a short form, 13-item PAM using iterative Rasch analysis, and found it to be reliable and valid, with minimal and acceptable decrease in precision of measurement compared to the 22-item PAM; statistical regression of the 13-item PAM scores on the 22-item PAM scores explained 92% of score variance.

Both the 13-item and 22-item PAM were tested using the same data, which included 1,515 adults aged 45 to 97 years old, 63% female, 50% with high school education or less, 32% with household income less than \$25,000 a year, 88% Caucasian, and 79% with at least one chronic disease. The authors reported no significant difference in outcome between people completing the PAM in person versus over the telephone (Hibbard et al., 2004).

The PAM is an interval level scale, with the ascending order of questions indicating ascending level of activation. For example, agreement with only the first item on the PAM indicates low activation, whereas agreement with subsequent items on the PAM indicates increasingly higher levels of activation. The PAM is scored by adding responses for each question: *strongly disagree* scores 1 point, *disagree* scores 2 points, *agree* scores 3 points, and *strongly agree* scores 4 points. The total score is converted into the person's activation score using a calibration table derived from test data, resulting in a score of 0-100, with a higher score

indicating higher activation (Hibbard et al., 2005). A person's activation score is then associated with one of four levels of activation, conceptualized as developing in order of: (1) believing one has an important active role in managing health; (2) possessing confidence and knowledge to take action; (3) taking action; and (4) maintaining healthy lifestyle under stress and change (Hibbard et al., 2005). The 13-item PAM questions with calibrations are published in Hibbard et al. (2005, p. 1923).

The PAM-13 has been used with rural populations (Hung et al., 2013) and people living with HIV in the United States (Marshall et al., 2013). An assessment of the PAM-13 with a telephone survey of 812 rural participants found the PAM-13 to have convergent and divergent validity, high person and item reliability; however, there may be a ceiling effect in not being able to assess change in activation for people with initially high activation (Hung et al., 2013). Marshall et al. (2013) found that higher PAM-13 scores were associated with better clinical outcomes. A five-point increase on the PAM was associated with having better odds of a stronger immune system, HIV viral suppression and adherence to HAART (Marshall et al., 2013).

Access and use of telephone and Internet for personal use questionnaire. Access to telephone, cellular phone and Internet access for personal use, including where, and on what devices participants access the Internet, further describes participants' context and may relate to patterns of need between those participants with or without access to information via the Internet or telephone, for personal use. Additionally, surveying participants using questions from the UTAUT2 model (Venkatesh et al., 2012, p. 178) for predicting intention and use of the Internet for personal use may provide insight into participants' likelihood to use health services via personal Internet. A survey was created to determine participants': (a) access to a telephone for

personal use; (b) access to the Internet for personal use; (c) years of experience using the Internet; (d) frequency, locations and devices used to access the Internet for personal use; and (e) answers to questions that represent constructs from the UTAUT2 (Venkatesh et al., 2012).

Participants who indicated never using the Internet were asked if they have ever accessed the Internet in the past, why they do not use the Internet, and their thoughts about the Internet in general. The survey is attached in Appendix E. Questions from the UTAUT2 model were adapted (Venkatesh et al., 2012, p. 178) and used with permission from V. Venkatesh (personal communication, February 1, 2016).

Demographics and history questionnaire. Participant demographics and HIV history was collected for two purposes. First, descriptive statistics were sought to characterize participants, and to describe their socio-economic context. Second, demographic data considered with qualitative needs data sought to indicate what characteristics of participants might be associated with particular identified needs. Data collected included self-reported: current age, sex, sexual orientation, use of intravenous drugs, citizenship and country of origin, Indigenous identity, annual income, employment activity, level of education, local access to primary care health professional, years living with HIV diagnosis, status of being prescribed and taking HAART, current region of residence, current marital status, household make up, and current perceived health status. Region of residence was derived from postal code information and is described under *Inclusion criteria* in detail. The following sections describe the rationale for each characteristic collected and how it relates to living with HIV in Canada.

Known population risk factors. Although HIV can infect anyone, certain factors may increase a person's risk of infection or likelihood of exposure. For example, the Government of Canada (2006c) identifies the following key populations as being at risk or disproportionately

affected by HIV: gay, bisexual, two-spirit and other men who have sex with men; people who inject drugs; people in prison; at risk youth; Indigenous people; women; and people from countries where HIV is endemic.

Age. Health related HIV needs may differ based on age (Bernardin et al., 2013; Krentz & Gill, 2015). Women over 40 years old have indicated the need for increased services related to HIV (Bernardin et al., 2013). Also, Krentz & Gill (2015) found that adults living with HIV 50 years and older had more health related needs and increased health system costs compared to adults under 50 years of age.

Socio-economic factors. Structural socio-economic factors such as low income, less education, and unemployment are also associated with higher risk of HIV infection and reduced access to care (Millett et al., 2012). Level of education also may be a factor in activation and self-management of HIV. Activation, measured by the PAM, was found to be lower in people living with HIV without a high school diploma, versus those who had completed high school (Marshall et al., 2013).

HIV history and region of residence. Collecting information regarding HIV history, like year diagnosed as HIV positive, whether or not they are prescribed and taking HAART, perceived health status and geographic demographics such as region of residence, better describes participant needs in context. For example, taking HAART routinely as prescribed is key for successful management of the HIV virus, and the goal of HAART treatment is an undetectable viral load (Manitoba HIV Program, 2017). Depending on the type of HAART a person is taking, between 70% - 95% adherence may be required for full viral suppression and avoidance of drug resistance (National Collaborating Centre for Infectious Diseases, 2010). Being able to adhere to routine HAART prevents immune suppression and poor health status that

is associated with higher morbidity and mortality, but may require access to additional supports (Canadian Working Group on HIV and Rehabilitation, 2015). A multilevel modeling study of 25,585 cases with a new HIV diagnosis in Florida determined that later diagnosis of HIV infection is more common in rural versus urban counterparts, and is known to be associated with more disease related problems (Trepka et al., 2014). This is consistent with findings in Manitoba that people living outside of Winnipeg are more likely to present to care with advance HIV infection (Manitoba HIV Program, 2016, 2017), and are therefore the focus of this study.

Household support. Marital status and household living environment provides a quantitative description of participants' context and may relate to patterns of different needs between groups of participants, for example married versus unmarried, and with or without dependents. For example, parents with HIV may need supports related to childcare in order to access certain services and supports. Also, a survival analysis of American longitudinal population data found that unmarried and divorced or separated men were more at risk for HIV/AIDS mortality (Kposowa, 2013), suggesting the potential for unmet needs and supports.

Qualitative design. An interpretive description approach was used via semi-structured interviews, conducted by telephone or in person, with adults living with HIV outside of Winnipeg, who were connected with the Manitoba HIV Program. Interpretive description is supported as a method for understanding the health and illness experience of those people living with a particular condition, while recognizing the influence of context on that experience (Thorne, 2016). Originally conceptualized in the literature by nursing researchers (Thorne et al., 1997), interpretive description has been embraced by other allied health professionals (Archibald, Caine, Ali, Hartling, & Scott, 2015; Brewer, Harwood, McCann, Crengle, & Worrall, 2014; Fricke, 2016) as an applied approach to developing discipline knowledge about

“real-world” clinical questions (Thorne, 2016, p. 40). Recent studies using interpretive description include understanding information needs of parents of children with asthma (Archibald et al., 2015), and collaborative research with Indigenous people (Brewer et al., 2014; Fricke, 2016). Interpretive description does not prescribe any one theoretical framework, but suggests matching methods with research questions (Thorne, 2016); for example, in this study, using a needs assessment approach to understand needs. The description of the phenomenon is interpreted in light of a specific discipline approach, recognizing the intrinsic involvement of the researcher, and aims to understand a research question in context sufficiently to guide future practice (Thorne, 2016).

Individual, semi-structured interviews were chosen to explore participants’ needs. Interviews were conducted by telephone or in person, to make interviews accessible and to provide options for involving people living with HIV in rural Manitoba as experts in their own needs (Jordan, Dowswell, Harrison, Lilford, & Mort, 1998). In-person interviews in the participant’s home or community would allow ideal observation of the participant’s context, but were cost prohibitive due to travel expenses. Although focus groups are time efficient in hearing from multiple participants at once, individual interviews were chosen to ensure each participant’s voice was heard clearly and thoroughly, to meet study objectives, and avoid additional marginalization (Jordan et al., 1998; Patton, 2015).

Sample. According to Paton (2015), the sampling strategy and size for qualitative studies are guided by the purpose of the study. This study used purposeful sampling, with a proposed sample size of 16 to 24 people. A flexible, emergent design was used to respond and react to data revealed during the study (Patton, 2015). The following section describes and justifies the study sampling strategy and size in further detail.

Sampling strategy. Qualitative, purposeful sampling aims to understand a small number of participants in greater depth to answer a research question, instead of attempting to get a general idea of all participants in a population (Patton, 2015). People with lived experience of a health condition are considered experts about their experience; however, participants differ in their articulation and processing of their experiences and intertwine experiences with other aspects of their life (Thorne et al., 1997). Purposeful selection of participants who have shared elements of experience is recommended for interpretive description (Thorne, 2016). To better understand the unmet rehabilitation needs, resources and barriers of adults living with HIV outside of Winnipeg in Manitoba, patients connected with the Manitoba HIV Program were purposefully selected. At the time of the study, the Manitoba HIV Program operated out of two main clinical sites located in Winnipeg. One site was an internal medicine clinic situated within a large tertiary care hospital; the other was a community primary health care centre specializing in HIV prevention and care, and other sexually transmitted blood borne infections.

Sampling included being open to an emergent subgroup having similar or critical needs, and elaboration sampling to further understand the subgroup. According to Patton (2015), this means: (a) defining a study sample after some data collection because the data will reveal the importance of needs for a specific group, and (b) adding participants to the sample to fully explore a specific group's needs in relation to the research questions. Given the study purpose to explore, identify and prioritize the rehabilitation needs of adults living with HIV in non-metropolitan Manitoba, purposeful sampling facilitated the study goal of creating a catalogue illustrating the range of needs, resources and barriers of the participants, with the aim of using data for creating solutions to meet needs through further study.

Sample size. Similar to selecting a sampling strategy, there are no set rules for determining adequate sample size for qualitative studies (Patton, 2015). Patton supports Lincoln and Gubba's criteria of sampling to redundancy (2015, pp. 300–301). For this study, the absence of new needs, barriers or resources being identified in analysis of interview transcripts indicated data redundancy. If the sample of participants is too homogeneous, data redundancy may be falsely identified. Descriptive analysis of demographics helped to prevent false redundancy. An absence of a clear pattern of needs or priorities may indicate the sample of participants is too varied and suggest the need to focus on a subgroup. Sampling to redundancy is not predictable; however, for a successful study, minimum sample size should be estimated to allow adequate study planning based on what is needed to reach study purpose and goals (Patton, 2015). This study proposed a minimum sample size of $N = 16$.

The number of adults living with HIV in rural Manitoba is unknown. At the end of 2015, the Government of Manitoba et al. (2016) estimated approximately 2,117 people were living with HIV province-wide. Twenty-one percent of new HIV cases over the past four years were people living in one of the four health regions outside of Winnipeg (Government of Manitoba et al., 2016; Manitoba HIV Program, 2017). Although possibly an overestimate, 21% of 2,117 equals 445 people living with HIV in rural Manitoba. The Government of Manitoba et al. did note, “an apparent shift in reporting of rural cases, as more are identified from areas outside of Winnipeg compared to previous years” (2014, p. 13). While the minimum sample of 16 is relatively small compared to the sample size required of a powerful quantitative study, gathering detailed qualitative information regarding needs of 16 or more adults living with HIV should produce a thorough catalogue of the range of needs for this population.

Inclusion criteria. Participants were eligible to participate if they were 18 years or older, had a diagnosis of HIV for six months or longer, lived outside of the city of Winnipeg, but within Manitoba, and had English language skills sufficient to understand study consent and participate in a verbal interview.

A potential participant's residential postal code, specifically their forward sortation area (FSA), was used to determine if they met the criteria of living outside the city of Winnipeg, but within Manitoba. A FSA is comprised of the first three characters of a Canadian Postal Code^{OM}, and represents a stable, geographic area (Canada Post, 2017). The second character of the FSA designates an area as either rural if equal to zero, or relatively urban if equal to one to nine. All postal codes in Manitoba begin with R (Statistics Canada, 2013b). Potential participants were excluded if they had a residential FSA associated with Winnipeg. Potential participants with all other Manitoba FSAs were considered for the study.

Both men and women were recruited for this study, with an aim to include equal numbers of participants from both groups. Sex is identified as an important criteria in the literature that may lead to differing needs between women and men living with HIV (Bernardin et al., 2013; Rapid Response Service, 2013a). Women living with HIV from rural areas in an American study, reported to have more concerns regarding disclosing their HIV status, and higher perceived stigma compared to men, or women living in non-rural areas (Gonzalez et al., 2009). Women in Canada tend to be diagnosed later than men with HIV (Csete & Canadian HIV/AIDS Legal Network, 2005), which may lead to more needs due to advanced disease progression. Women and men who have sex with men living with HIV in rural areas are more at risk for violence, perceived stigma and social isolation compared to peers living in urban areas (Rapid Response Service, 2013a).

Besides aiming to recruit equal numbers of men and women participants, no other characteristic was specifically sought. However, based on population data (Government of Manitoba et al., 2014) and known risk factors for HIV infection in Canada (Government of Canada & Public Health Agency of Canada, 2006b), it was anticipated that some participants who chose to participate may self-identify as Indigenous (i.e., First Nations, Métis, or Inuit; Statistics Canada, 2013a). In conjunction with submitting this study for review by the Health Research Ethics Board at the University of Manitoba, a letter of information was sent to the Assembly of Manitoba Chiefs. The letter informed the Assembly of Manitoba Chiefs of the study proposal, and anticipated inclusion of participants who may self-identify as Indigenous, First Nations or Métis. The letter included that no specific analysis was planned to focus on outcomes based on self-report of participants' ethnicity.

Exclusion Criteria. Adults who otherwise met the criteria of the study were excluded if they were not legally in charge of making or communicating their own medical decisions.

Procedures

The following section describes recruitment strategies, participant contact procedures, and interview procedures.

Recruitment strategies. Recruitment of participants occurred in multiple ways.

- The principal investigator arranged meetings with care providers of the Manitoba HIV program and informed them of the study purpose, objectives and procedures.
- Primary care providers were asked to post posters in their waiting areas and offices, and provide verbal and written handout information to eligible participants.
- Information about the study and how to contact the research interviewer was posted at Nine Circles Community Health Centre with their permission.

- Posters and handouts briefly described the study and provided the principal investigator's contact information, including telephone number with confidential password protected voicemail and University of Manitoba e-mail address.
- The principal investigator scheduled time on-site at the Manitoba HIV Program to provide staff and interested participants information about the study upon request.
- During the study period, Manitoba HIV program clinic staff were asked to inform potential participants attending Winnipeg for an appointment, about the study, and handouts with written information were made available to those who were interested.

Additionally, the Manitoba HIV Program was involved in creating a population-based cohort of people living with HIV in Manitoba (Liddy et al., 2014). Prior to study recruitment, as of February 9, 2015, 425 people living with HIV in Manitoba had consented to be contacted regarding research events (L. McClarty, personal communication, February 12, 2015). During study recruitment, cohort staff informed cohort participants attending for appointments about the study and provided the study handout to those participants who were interested. Cohort staff communicated when cohort participant appointments were generally scheduled to facilitate when the principal investigator should be available for questions about the study.

Regarding being open to emergent subgroups with similar or critical needs, early on in the study it became apparent that women (1 out of the first 4 recruited) were more difficult to recruit, and that it was important to recruit participants living in rural areas versus small urban centres outside of Winnipeg to get a better understanding of barriers at a greater distance from services. The principal investigator worked with cohort staff to identify the best times to attend clinic when more women and rural residents (i.e., those with FSAs starting with R0) were scheduled to attend.

Participant contact. Potential participants who were interested were given the principal investigator's contact information. Potential participants in contact with the principal investigator were verbally screened for inclusion and exclusion criteria. Screening questions are documented in Appendix G. Participants who met the criteria received verbal details of the study and a copy of the research participant information and consent form (Appendix H) if they were interested, either by mail or e-mail, according to their preference. Study consent was reviewed in detail and with explanation as needed, with interested potential participants either in person, or by telephone to facilitate people with various levels of literacy. Consent was signed in person by both the participant and principal investigator, or documented over the telephone by the principal investigator. A copy of signed consent was provided to each participant. With consent, the principal investigator booked an interview time with the participant according to their availability and preference. Interviews were offered by telephone, or in-person at one of the Manitoba HIV Program sites or University of Manitoba Bannatyne Campus, in order to facilitate participation and choice.

Interview and questionnaire procedures. Once signed consent was received, interview times were booked with each participant. Semi-structured interviews were conducted with each participant, with the goal of understanding participant activity and social participation needs, barriers and resources. A semi-structured interview guide was used, but with an emergent, iterative design in order to uncover any unanticipated needs of participants. The second last question of the semi-structured interview guide cued the interviewer to have the participant identify their *three most important needs* from the interview as a whole. These needs were recorded and confirmed with each participant prior to ending the interview. Dated versions of the interview guide were saved as part of the study audit trail. The final version of the interview

guide is included in Appendix I. Interviews were audio recorded for transcription. In person interviews occurred in a private room at the University of Manitoba Bannatyne Campus. Following the semi-structured qualitative interview, participants completed self-report questionnaires of the PAM-13, access and use of telephone and Internet for personal use, and demographics and HIV history. To maintain consistency of how questionnaire data was collected, the principal investigator read the questions to participants and recorded their verbal responses in writing regardless if the participant was interviewed over the telephone or in person. The principal investigator explained questionnaire terminology for any participants who had questions or demonstrated not understanding a question clearly.

Data Management

The following data were coded with a unique identification number and had participant-identifying information removed: demographics and history questionnaire, telephone and Internet access and use questionnaire, PAM-13, verbatim-transcribed interview and notes, field notes, journal and audit trail. The coded identity data are stored in a locked file cabinet, in a locked office of the principal investigator's supervisor at the University of Manitoba. As a security measure to protect participant anonymity, signed consent forms, audio recordings and a master list to matching coded data with participant names are stored separately from coded data.

Field notes were documented after each interview to track interview process observations. The interviewer completed field notes as soon as practical following each interview. The field note is a typed document coded with the corresponding participant identifier. Field notes include context of the interview, highlights of interview content, interviewer observations, interpretations, comments on interview process, utility, and any notes regarding interview process.

The principal investigator kept a journal throughout the study to note observations and thoughts on the study. An audit trail document tracked steps taken from study design to study completion. All documents are held on a password-protected computer in the locked office of the principal investigator's supervisor's at the University of Manitoba, including a back-up copy of study data on a password protected, encrypted drive.

Data Analysis

Data analysis for embedded, concurrent mixed methods research involves analysis of the quantitative data (secondary strand), qualitative data (primary strand), and the merged results of qualitative and quantitative strands (Creswell & Plano Clark, 2011). The following sections outline the data analysis process that addressed quantitative, qualitative, and mixed methods research questions for this study. Although different analysis procedures are indicated for quantitative and qualitative data, both involve the following steps according to Creswell and Plano Clark (2011, pp. 204–210): prepare, explore, analyse, represent, interpret and validate.

Quantitative data analysis. Demographics, HIV history, telephone and Internet access and use, and PAM-13 data were summarized to describe the sample of participants.

Prepare. To prepare quantitative data for analysis, values were assigned to demographic, HIV history, and telephone and Internet access and use responses with ordinal or nominal data types. A quantitative codebook was created including variable names, labels, definitions, type and width of data, value codes, missing codes, and range of responses. The PAM-13 was scored according to the developers instructions and a Microsoft Excel spreadsheet provided with the PAM-13 license (Hibbard et al., 2005, 2004). Quantitative data were entered into and managed using Research Electronic Data Capture (REDCap; P. A. Harris et al., 2009).

Explore. Data were visually scanned for inconsistencies, in addition to measures taken to ensure accurate data collection and entry as described below in *Validate*. Frequencies and description of the study sample demographics, HIV history, telephone and Internet access and use, and patient activation level were calculated.

Analyse. Analysis of quantitative strand data was limited to descriptive analysis due to the small sample size. Measures of central tendency were calculated for nominal, ordinal, interval and ratio data collected from the demographic survey, survey of telephone and Internet access and use, and PAM-13 scores. Similarly, ranges and standard deviation were calculated where appropriate to better describe the study sample, but with no intention to generalize to the whole population of people living with HIV outside of Winnipeg, in Manitoba.

Represent. Results describe the summary statistics and frequency responses of the participants who participated in the study. Tables and figures are also used to represent some of the quantitative data where deemed efficient. Results will compare the study sample of participants with available provincial epidemiology reports.

Interpret. Descriptive statistics were interpreted with caution due to the small sample size, and primarily used to better understand participants' context.

Validate. The sample size of $N = 17$, although sufficiently large for a qualitative study, is insufficient for a powerful, quantitative study. Additionally, the purposeful versus random sampling strategy diminishes the generalizability of quantitative results. However, to ensure validity of descriptive statistics, actions were taken to support accurate data through strategies related to data collection and data entry that are described below.

Data collection strategies. Demographic, HIV history, and telephone and Internet access and use surveys were designed to be easy to read, with a minimum 12-point font, and sufficient

space on the page. Surveys were printed one-sided to avoid missed pages (Schneider & Deenan, 2004). A post-interview and data collection checklist was used with each participant to reduce missed items (Schneider & Deenan, 2004).

Data entry. A quantitative codebook was used for data coding and included a document to track data entry decisions during the study. Data were entered into set electronic forms designed to match the surveys using REDCap (P. A. Harris et al., 2009). Data spreadsheets generated by REDCap included variable labels that matched the name and order of data collection forms. Data entry forms were set up to only allow select entry ranges from dropdown menus appropriate per item. Data were entered twice, at different sittings, then compared electronically to flag and address any data entry errors (Schneider & Deenan, 2004).

Qualitative data analysis. Interpretive description explores "...a clinical phenomenon with the goal of identifying themes and patterns among subjective perspectives, while also accounting for variations between individuals" (Hunt, 2009, p. 1285). This study aimed for a clear description of the needs, barriers and resources from the perspective of adults living with HIV in rural Manitoba. To achieve this aim, Thorne (2000) recommends *constant comparative analysis*. Each interview transcript was read and compared with each other interview iteratively for similarities, differences and relationships between experiences. Memos were noted throughout the process and coding changed iteratively with each interview pass. If a new code was found in an interview, previous interviews were reviewed for similar instances and coded accordingly. Low inference interpretation of needs was facilitated by using the language of the participants (i.e., *in vivo* coding), whereas broader questioning during comparative analysis sought to interpret contextual influences and differences between participants. The outcome of the analysis is a description (Sullivan-Bolyai et al., 2005) of the prioritized needs of adults living

with HIV in rural Manitoba, as determined by the participants, with an interpreted description of the context to inform future practice and intervention.

Prepare. A paid research transcriptionist transcribed the digital audio-recorded interviews verbatim into documents, with participant identifying information removed. Transcripts were reviewed for accuracy by the interviewer and edited accordingly. Each transcript document was labeled with unique participant code and the date of the interview. Notes from each interview were reviewed and integrated into a corresponding field note. Study data and documents were organized using NVivo 10 qualitative data analysis software (QSR International Pty Ltd., 2012).

Explore. Exploration of interview transcripts, field notes and study journal was iterative. As transcripts became available and checked for accuracy, they were reviewed again to gain a sense of the interview as a whole, with initial analysis thoughts noted in memos associated with each transcript and field note. An initial codebook was developed with code labels and operating definitions, but evolved iteratively. The codebook was initially organized according to the qualitative research questions; however, these initial codes were replaced with *in vivo* codes as analysis proceeded. One exception was the second last question from the semi-structured interview guide where participants identified their three most important needs from the interview as a whole. Each participant's needs were coded *in vivo* according to their first, second and third choices in a separate node in the study's NVivo project.

Analyse. Qualitative content analysis (Patton, 2015) was conducted using *in vivo* coding to ensure low-inference presentation of needs, resources, barriers and solutions from the perspectives of the participants. Codes were initially generated from transcribed interviews, using participants' exact language, and continuously modified to integrate new data throughout collection. Codes were further organized into themes, and larger interpreted perspectives of

context that emerged from patterns identified in the interview data after numerous comparisons. Prioritized needs, identified by participants near the end of semi-structured interviews, were collected under one node for analysis. Prioritized needs were reviewed one-by-one and grouped together with similar needs identified by other participants. Once all similar needs were grouped together, each grouping was reviewed for consistency and an overall theme. Groupings and themes were initially determined by the principal investigator, then reconsidered and reviewed for fit and possible alternatives through discussions and feedback from the thesis supervisor.

Represent. Description and summary of qualitative analysis is discussed in the results, including presentation of qualitative study data to support evidence of emergent themes from participant interviews. A table demonstrating the frequency of priority needs identified by participants is included in the joint display of mixed qualitative and quantitative results.

Interpret. Qualitative strand data is interpreted and presented in the discussion. Interpretation of the data in relation to the qualitative research questions, previous research, and in the context of existing theories is described.

Trustworthiness. Schwandt defines validity, or trustworthiness in qualitative research as “how accurately the account represents participants’ realities of the social phenomena and is credible to them” (as cited in Creswell & Miller, 2000, p. 124-5). In the context of this study, the social phenomena are the needs, contributing factors and priorities of people living with HIV in rural Manitoba. Unlike quantitative validity, trustworthiness in qualitative research is achieved by strategies that produce accurate, credible interpretation and presentation of the data, as opposed to verifying the data itself, alone (Creswell & Miller, 2000). Although numerous strategies for trustworthiness exist, this study applied a framework presented by Creswell and Miller (2000) and justified the following procedures applying specifically to this study: member

checking, disconfirming evidence, research reflexivity, audit trail, rich description, and thesis committee supervision and review.

Creswell and Miller (2000) describe a framework for selecting validity procedures based on validating study results from the perspective of the participants, the researcher, and external reviewers, as well as based on the worldviews guiding the study. Given the context of the study, as a thesis, conducted by a student researcher with a pragmatic, transformative approach aiming to facilitate change for people living with HIV in rural Manitoba, procedures that facilitate trustworthiness from the perspective of the participants, the principal investigator and external reviewers were warranted. Additionally, a systematic approach to trustworthiness and a critical paradigm guided procedures to meet the demands of academic rigour. Selecting procedures for trustworthiness related to the perspectives of participants, external reviewers and the principal investigator contribute to authenticity and transferability of interpretations. The following procedures were applied to develop trustworthiness from multiple perspectives and worldviews, and are explained in the context of this study's design.

Member checking. Interpretive description aims to construct a “tentative truth claim” (Thorne et al., 2004, p. 6) between participants and the researcher. Member checking in this study involved two processes. First, participants confirmed their assignment of priority to their needs at the end of each interview. Second, participants who consented were sent and/or read an aggregate summary of the study findings for their review and had the opportunity to (1) confirm if the study findings represented their perspective, and (2) add any additional information or feedback. Participants chose how they wanted to receive the summary findings. For those participants who preferred the summary to be mailed, postage paid return addressed envelopes were provided to facilitate return of additional information. Participants receiving summaries by

mail were also given the options of telephoning the principal investigator or e-mailing any additional information. The principal investigator also offered to read the summary to participants. A couple participants preferred to receive the summary by email. Three participants requested to meet with the principal investigator in person at their next appointment in Winnipeg, once the summary was ready. Three participants did not want to receive a summary. Participants were asked to provide feedback within two weeks of receiving the summary. Two participants responded with additional feedback that was incorporated into the findings. One summary was returned unopened indicating the participant had moved.

Researcher reflexivity. The principal investigator kept a reflexive journal throughout the study, noting biases, preconceptions and ideas to be considered in analysis. Regular meetings with thesis supervisor also encouraged reflexivity throughout the study.

Disconfirming evidence. Once analysis reached initial themes, the principal investigator reviewed transcripts, field notes and journals with the goal of identifying disconfirming evidence. This process contributed to identifying subgroups of participants interviewed, as well as unique experiences or contexts that differed from common patterns and themes.

Audit trail. Research activities and decisions were documented throughout the study. The audit trail is composed of documents that are a chronological reflection of journaling, research study log of process and data collection events, as well as analysis memos, process and procedures.

Rich description of participants in context. Descriptive statistics helped identify participants as a relatively heterogeneous group in relation to characteristics such as age, sex, and region of residence. Journal observations and field notes from interviews contributed contextual data for the study report.

Thesis supervision and review. This study was completed in partial fulfillment of a Masters of Science degree and was subject to thesis committee supervision, review and evaluation. The thesis supervisor read all interview transcripts and reviewed coding. The principal investigator and thesis supervisor met on several occasions to discuss findings and interpretations. The supervision of the study process served to balance the principal investigator's assumptions and help support the validity of the findings. The context of academic regulations provided a structured review process to ensure quality and accountability of the research study. Additionally, thesis committee members were approached with consideration for their diverse academic and professional backgrounds, as well as being experts in different areas related to this thesis research. The health care professions of occupational therapy, nursing and medicine were represented within the thesis committee, and included research experts in areas of HIV, rehabilitation, ICTs, and qualitative and quantitative methods. This diversity of perspectives among committee members contributed to exploring and analyzing the results for additional interpretations of the findings, and to the trustworthiness of the study.

Mixed methods data analysis. Qualitative and quantitative data analysis were merged and are presented in a joint display as described by Creswell and Plano Clark (2011, p. 226), to address the mixed methods research questions identified for this study. A joint display is a matrix table that relates qualitative themes on one axis, with corresponding quantitative data on the other axis, such as participants' age, sex, or years since diagnosis. NVivo 10 qualitative data analysis software (QSR International Pty Ltd., 2012), and selected data export from REDCap (P. A. Harris et al., 2009) to Microsoft Excel (2011), was used to organize and compare related frequency of responses related to qualitative needs and quantitative characteristics. The following dimensions were analysed:

1. Qualitative themes of priority needs versus socio-demographic characteristics:
mean age, gender, education level, income level, marital status, rural versus small urban centre residence, recruitment site, and telephone and Internet access;
2. Qualitative themes of priority needs versus self-reported health characteristics:
mean years living with HIV, general health, and level of HIV control;
3. Qualitative themes of priority needs versus PAM-13 score and level.

Mixed methods results are considered in the context of existing theories and previous research. Congruence and discrepancies are noted and discussed. The results are considered related to next steps for addressing unmet needs in the context studied.

Ethics

Ethics approval for this study was obtained from the Health Research Ethics Board at the University of Manitoba. Approval was also received from organizations involved in the study (Health Sciences Centre, Winnipeg; Nine Circles Community Health Centre, Winnipeg). A process of informed, ongoing consent was used (Munhall, 2012, p. 496). Participants were reminded at the onset of all points of interaction during the study that participation was voluntary and could be withdrawn at any time, without effect on their care or services. Consent information was provided verbally and in writing. The consent form is attached in Appendix H, and was reviewed in detail with each participant prior to obtaining their written consent. The burden of participating in the study was considered to make participating accessible, including the physical, emotional and economic resources required to participate. In order to compensate participants for approximately two hours of their time, and potential cost of telephone use, this study provided each participant with \$60.00 Canadian currency cash, upon completion of the interview.

Feasibility

Members of minority groups may experience health disparity (Sullivan-Bolyai et al., 2005). Adults living with HIV in rural Manitoba may experience health disparity related to social factors such as stigma (Rapid Response Service, 2013a), and less access to quality, available HIV services (Sullivan-Bolyai et al., 2005). Additionally, the literature suggests that HIV research and resources were initially focused in areas of highest prevalence (i.e., cities), and notes the challenge of addressing the diversity and isolation of relatively low prevalence, geographically distant areas where rural living people with HIV reside (Berry, 2000; Pellowski, 2013; Worthington et al., 2009; Zukoski et al., 2011). The main threat to research involving hard-to-reach participants is recruitment and retention (McCullagh, Sanon, & Cohen, 2014). Challenges to successful recruitment noted in the literature include: suspicion and mistrust of research, transportation issues, burden of participating on finances and time, burden of disease, lack of understanding research goals, risks and benefits, limited or no access to communication devices required to participate, language and cultural differences (McCullagh et al., 2014). Table 1 outlines these challenges and the strategies this study used to successfully recruit the minimum sample size.

Table 1. Recruitment Challenges and Strategies

Challenge	Strategy
Suspicion and mistrust of research.	<ul style="list-style-type: none"> • Approval from University of Manitoba and clinic site ethics boards prior to initiating study activities. • Associate study with known and trusted primary care providers and specialists at the Manitoba HIV program sites. • Posters, handouts and website information regarding the study at the Manitoba HIV program sites. • Educate program staff re: study and encourage mentioning to potential eligible participants. • Research interviewer to be present and visible to provide clear, transparent information of study goals, risks and benefits. • Member checking with participants via summary of study findings for review and follow-up feedback prior to finalizing results.
Burden of participating on finances, time and existing health issues.	<ul style="list-style-type: none"> • Allow participants to choose time, place and method of participating to suit their needs and schedule. • Provide honorarium to compensate participants for their time. • Provide honorarium to compensate for telephone minutes to facilitate participation by phone interview; arrange for pre-paid minutes or telephone access locally for participants if needed.
No access to communication devices required for participating.	<ul style="list-style-type: none"> • Provide option of participating in person while attending Winnipeg for other appointments. • Provide honorarium to compensate for telephone minutes to facilitate participation by phone interview; arrange for pre-paid minutes for participants if needed. • Work with local primary care providers and participant to arrange access to communication devices in a private setting in the participant's community (e.g., telephone at health centre), if needed.
Transportation issues.	<ul style="list-style-type: none"> • Provide participants with option of interviewing by phone, videoconference or in person. • Provide participants with bus tickets to facilitate transportation to and from interview while attending Winnipeg, if needed.
Lack of understanding research goals, risks and benefits.	<ul style="list-style-type: none"> • Review consent form prior to participating. • Provide clear, transparent information regarding study goal, risk, benefits, use and care of data. • Ensure participants are aware of their right to withdraw from study at any time without consequence.
Language and cultural differences.	<ul style="list-style-type: none"> • Research interviewer is licensed occupational therapist with over ten years of experience working in health and community settings, including cultural awareness and sensitivity training. • Research interviewer experienced working in urban, rural and remote Northern communities with clients from multicultural backgrounds.

Chapter 4: Findings

The quantitative, qualitative and mixed findings are included in this chapter. Although the qualitative part of the study is the leading emphasized strand, the secondary, quantitative strand of the study is described and presented first in the findings. Although not generalizable to the larger population, the quantitative description will situate the context of the qualitative findings.

Quantitative Findings: Participants

Seventeen participants completed the study between August 2016 and end of March 2017. Eight of the 17 participants completed interviews and questionnaires via telephone; the remaining nine participants completed the interviews and questionnaires in person. Interviews and collection of questionnaires were audio recorded and had a total average length of 1 hr 13 min (range = 29 min to 2 hr 26 min). The time to complete questionnaires ranged from 10 min to 45 min, however it is important to note that participants were not discouraged from adding additional qualitative content if it occurred to them while answering the questionnaires. Median questionnaire time was 14 min, and was calculated instead of mean time to account for the one outlier maximum time that was 20 minutes longer than the next nearest completion time. More than half ($n = 11$, 65%) of participants were recruited from the internal medicine clinic site at a large tertiary care hospital in Winnipeg; the remaining six (35%) participants heard about the study, directly or indirectly, from posters and handbills posted at the Winnipeg based primary care centre site specializing in sexually transmitted blood borne infections.

Resident location in Manitoba. Participants resided in nine unique postal forward sortation areas; 11 reported residential postal codes starting with R0, indicating they lived in a rural area of the province (Statistics Canada, 2013b). The other six participants reported

residential postal codes from four unique small urban centres within the province, but outside of Winnipeg. Participants came from all four health regions that operate outside of Winnipeg in Manitoba: Northern ($n = 3$), Interlake-Eastern ($n = 9$), Southern ($n = 2$), and Prairie Mountain ($n = 3$). However, the women who participated in the study came from Interlake-Eastern and Prairie Mountain regions only.

Self-report identity characteristics. Table 2 outlines self-report identity characteristics collected from participants. To protect participant identity, minimum and maximum age of participants is not reported. Participants had a median age of 47 years. Almost two thirds ($n = 11$, 65%) of the participants considered themselves to be an Indigenous person (i.e., North American First Nations, Métis, Inuit, status or non-status). Fifty-nine percent ($n = 10$) of participants self-identified as men; the remaining participants self-identified as women. All participants in this study reported being cisgender, with no participants self-reporting as transgender, transsexual or a person with a history of transitioning sex. Thirteen (76%) participants self-reported heterosexual sexual orientation, where remaining participants ($n = 4$, 24%) identified as gay, bisexual or chose not to respond. Participants had been living with HIV for an average of 12 years at the time of interviewing. To protect participant identity, minimum and maximum years since diagnosis is not reported. Participant duration of living with HIV in years is illustrated in Table 2 using aggregate categories of years since diagnosis.

Socio-economic status characteristics. Table 2 includes self-report participant characteristics about highest level of education completed, current main employment, marital status and annual income. Participant report of their current main employment was varied. Four (24%) participants report working a paid job as their main activity; however, two (12%) participants said they receive a disability benefit and work “under the table”. Long-term illness

was noted as the main activity for four (24%) participants who all received a related benefit income. Only two (12%) participants lived with children in their home. Almost a quarter ($n = 4$, 24%) of participants reported living alone; six (35%) participants reported living with one other person, four (24%) lived with two other people, and three (18%) lived with three to six others in their home. The most frequently reported yearly household income was \$10,000 to \$19,999 ($n = 7$, 41%).

Table 2. Participant Characteristics, N = 17

Characteristic	n (%)
Age category	
Young adult, 18 – 34 years	2 (12)
Adult, 35 – 54 years	9 (53)
Older adult, 55 – 74 years	6 (35)
Male gender	10 (59)
Identify as Indigenous	11 (65)
Years since HIV diagnosis	
0.5 ^a – 5 years	4 (24)
6 – 10 years	3 (18)
11 – 15 years	6 (35)
16 – 20 years	2 (12)
> 20 years	2 (12)
Education	
Some school	6 (35)
High school or equivalent	4 (24)
College or technical diploma	5 (29)
University degree(s)	2 (12)
Current main employment	
Working	4 (24)
Long term disability	4 (24)
Caring for a family member	2 (12)
Volunteering	2 (12)
Retired	2 (12)
Looking for work	1 (6)
Marital status	
Never married	7 (42)
Married or common-law	5 (29)
Separated or divorced	3 (18)
Widowed	2 (12)
Annual income	
≤ \$19,999	8 (47)
\$20,000 - \$59,999	3 (18)
\$60,000 - \$99,999	3 (18)
≥ \$100,000	2 (12)
Did not know	1 (6)

Note. Due to rounding, some totals may not correspond with the sum of separate figures.

^a Study inclusion criteria required that all participants be diagnosed with HIV for at least six months.

Self-reported health, treatment and co-morbidities. Table 3 lists the frequency of responses for self-report general health and HIV control, taking of HAART, history of intravenous drug use, and co-morbid health conditions. The majority of participants ($n = 13$, 76%) report having at least one other health condition in addition to their HIV diagnosis. The following is a list of other health conditions participants report: metabolic disorder, high cholesterol, hypertension, diabetes, hepatitis C, neuropathy, arthritis, mood disorder, substance use disorder, conditions affecting breathing and circulation, tremors, cancer, organ failure, skin conditions, and conditions affecting vision. Five of the 13 participants (38%) reporting other health conditions explicitly stated they felt at least one of their health conditions was caused by HIV or was a side effect of the treatment for HIV.

Participants spoke about symptoms and impairments related to HIV, medications or co-morbid conditions that impacted their daily activities. These symptoms and impairments were typically current or recurrent, although some were historical or related to past episodes of exacerbated illness. Reported physical symptoms and impairments included shortness of breath, speech impairment, fatigue, leg swelling, diarrhea, and vomiting. Cognitive symptoms and impairments included drowsiness and memory lapses; typically both were attributed to treatment side effects. Reported neurological symptoms and impairments included: decreased sensation and function of extremities, resulting in dropping objects or falling; tinnitus; vertigo and dizziness resulting in poor balance and falls; and pain. Some participants reported interruption to daily activities from negative reactions to certain treatment medications, or having a peripherally inserted central catheter for ongoing co-morbid treatments. Finally, several participants spoke about uncertainty and stress: wondering if medications would continue to work for them; if side

effects would interrupt their daily activities; the stress of working and managing health, versus not working and having less money.

Finally, Table 3 notes frequency responses related to access to regular and HIV specialist care providers, methods of travel required to attend appointments outside their home community and use of Telehealth as an alternative to travelling out of community for appointments.

Table 3. Participant Report of Health, Access to Treatment, and Co-morbidities, $N = 17$

Characteristics of health and access to health services	<i>n</i> (%)
Self-report of general health	
Excellent	1 (6)
Very good	6 (35)
Good	7 (41)
Fair	2 (12)
Poor	1 (6)
On highly active antiretroviral therapy	17 (100)
Self-report of how well their HIV is controlled	
Well controlled	12 (70)
Somewhat controlled	4 (24)
Not well controlled	1 (6)
History of or current use of non-prescribed injectable drugs	4 (24)
At least one co-morbid health condition in addition to HIV	13 (76)
Access a regular health care provider in home community	6 (35)
Access a specialist for their HIV	17 (100)
Require travel to see HIV specialist	17 (100)
Drive or are driven to specialist appointments	15 (88)
Fly by plane to specialist appointments	2 (12)
Attend specialist appointments by Telehealth instead of travel at times	3 (18)

Note. Due to rounding, some totals may not correspond with the sum of separate figures.

Access to primary care and HIV treatment specialists. Only six (35%) participants reported having a regular health care provider in their community. Three (18%) of these participants described their regular health care provider as a family doctor. The remaining three (18%) report their regular health care provider is a nurse (nurse practitioner, nurse at a local

health centre, or a community home care nurse). For the 11 (65%) participants who reported not having a regular health care provider in their community, reasons given are noted with response rates in Table 4.

Table 4. Reasons for Not Having a Regular Health Provider in Home Community, $n = 11$

Reason	n (%)
Do not need one, but have a usual place to go for care	3 (27)
No one available in the area	2 (18)
Do not want to see one in home community	2 (18)
Do not like the health care provider available, choose to go elsewhere or only see HIV specialist	2 (18)
Do not want to see a locum health care provider (i.e., a different health care provider each time)	1 (9)
Only want to see a health care provider who knows about HIV, choose to see HIV specialist only	1 (9)

Note. Due to rounding, some totals may not correspond with the sum of separate figures.

Quantitative Findings: PAM-13

All 17 participants completed the PAM-13 with no missing responses. The mean PAM-13 score was 67.1 ($SD = 9.2$) with a range of scores from 53.2 – 84.8. Table 5 outlines the category frequencies of participants' level of activation resulting from PAM-13 scores, where level 4 is the highest level of activation.

Table 5. Participant Level of Activation According to the PAM-13®, $N = 17$

PAM-13 Level of Activation	n (%)
1 – Disengaged and overwhelmed	0 (0)
2 – Becoming aware, but still struggling	2 (12)
3 – Taking action	10 (59)
4 – Maintaining behaviors and pushing further	5 (29)

Note. Due to rounding, some totals may not correspond with the sum of separate figures.

Although not generalizable due to the small sample size, it is interesting to note that participants scoring the lowest level on the PAM-13 were both older-adult men between the ages of 55 – 74, whereas both young adult women who participated in the study scored the highest level on the PAM-13, along with two adult men and one older adult man. The mean PAM-13 scores were similar between men ($n = 10, M = 67.9, SD = 10.9$) and women ($n = 7, M = 66, SD = 5.7$), although the scores for men were more varied than those for women. The participants receiving the highest scores on the PAM-13 (i.e., level 4) all had a high school diploma or higher. Participants scoring the highest level of activation on the PAM-13 reported diverse income ranging from \$10,000 - \$19,999 to \$100,000 or more; however, participants scoring the lowest level of activation both reported low income of \$10,000 - \$19,999 per year. PAM-13 activation level did not always align with participants' self-report of general health in this study; for example, both participants who scored level two reported to be in *very good* health, and the three participants reporting *poor* or *fair* health scored a level three on the PAM-13. Participants who scored level four reported their health was *good*, *very good* or *excellent*. With regards to participants' self-report of how well controlled was their HIV, all participants who scored a level four on the PAM-13 also reported their HIV was *well controlled*. However, the two participants who scored level two on the PAM-13 reported their HIV was *somewhat controlled* and *well controlled*. One participant who reported their HIV was *not well controlled* scored level three on the PAM-13. The remaining participants who scored level three on the PAM-13 reported their HIV was either *somewhat controlled* or *well controlled*. The average number of years living with HIV in relation to PAM-13 activation level was interesting in that the participants in this sample who scored level four, the highest level of activation, have been living with HIV for the least

amount of time. Table 6 depicts the average years living with HIV according to participants who scored the same level of activation on the PAM-13.

Table 6. Average Years Living With HIV According to PAM-13® Level of Activation, $N = 17$

PAM-13 Level of Activation	<i>n</i> (%)	Mean Years (<i>SD</i>)
1 – Disengaged and overwhelmed	0 (0)	
2 – Becoming aware, but still struggling	2 (12)	10 (1.5)
3 – Taking action	10 (59)	16 (6.4)
4 – Maintaining behaviors and pushing further	5 (29)	6 (3.3)
Total sample	17 (100)	12 (6.8)

Note. Due to rounding, some totals may not correspond with the sum of separate figures.

Quantitative Findings: Personal Access and Use of Telephone and Internet

Participants were interviewed about their access and use of personal telephone and Internet in a rural context, using both original and adapted questions from the UTAUT2 (Appendix F; Venkatesh et al., 2012). Table 7 reports participants' responses related to telephone and Internet access and use, years of Internet experience, main and secondary places the Internet is accessed, and devices used to access the Internet.

Table 7. Participant Access and Use of Telephone and Internet for Personal Use

Item	<i>n</i> (%)
Access and use of own telephone, <i>N</i> = 17	
Yes	14 (82)
No	3 (18)
Type of telephone, <i>n</i> = 14	
Cellular telephone only	8 (57)
Landline telephone only	4 (29)
Both cellular and landline telephone	2 (14)
Internet capable cellular telephone, <i>n</i> = 10	
Yes	7 (70)
No	3 (30)
Internet access for personal use, <i>N</i> = 17	
Never	3 (18)
Monthly	1 (6)
Weekly	2 (12)
Daily	11 (65)
Years of experience using Internet, <i>n</i> = 14	
< 5	2 (14)
5 – 9	3 (21)
10 – 14	2 (14)
15 – 19	4 (29)
≥ 20	3 (21)
Frequency of common devices used by participants to access the Internet, <i>n</i> = 14 ^a	
Desktop computer	9 (64)
Smart phone	6 (43)
Tablet	6 (43)
Laptop computer	5 (36)
Smart television	1 (7)
Where participants mainly access the Internet, <i>n</i> = 14	
Home	10 (71)
Family or friend's home	3 (21)
Work	1 (7)
Other places participants access the Internet, <i>n</i> = 14	
Public library	3 (21)
Family or friend's home	3 (21)
Place in community with free WiFi	3 (21)
In community using a paid service and a personal device (3G, 4G, LTE, etc.)	3 (21)
Community health centre	1 (7)
Work	1 (7)
Other – when in Winnipeg at places with free WiFi or computers	2 (14)

Note. Due to rounding, some totals may not correspond with the sum of separate figures.

^aEight participants used more than one device for accessing the Internet.

Access and use of telephone. The three (18%) participants without a telephone had a number that they used for messages, typically belonging to a family member or at a local health centre. One (7%) participant with only a landline described the telephone as shared with other residents and did not consider it appropriate for private conversations.

Access and use of the Internet for personal use. Three (18%) participants reported never accessing the Internet for personal use. All three reported not knowing how to use the Internet, but having seen family or friends use the Internet. Two of the three participants without Internet access indicated an interest in learning how to use the Internet, but noted cost as a barrier.

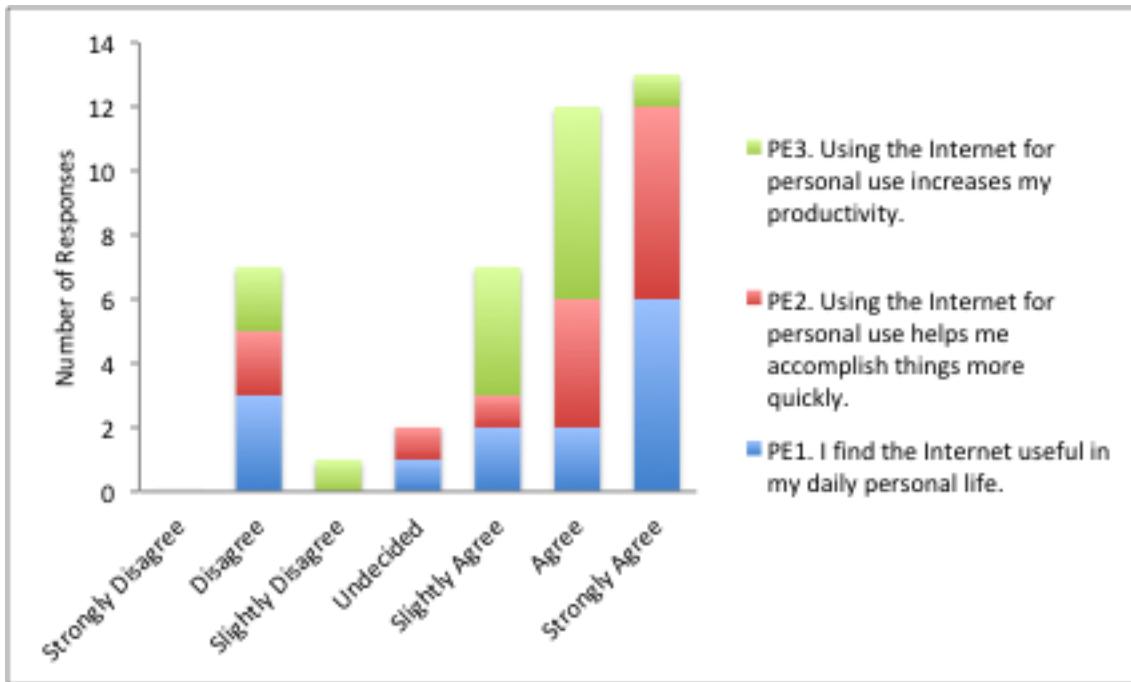
For the 14 participants with access to the Internet for personal use, years of experience using the Internet varied, with half of the Internet users (7, 50%) having used the Internet for 15 years or longer. Table 7 shows frequency response rates for categories of years of Internet experience.

UTAUT2 questions responses. UTAUT2 questions (Venkatesh et al., 2012) were adapted to survey participants about their intention and use of the Internet for personal use (Appendix F). Fourteen participants had access to the Internet for personal use and completed all of the UTAUT2 questions. Responses to each factor in the UTAUT2 model are reviewed below. Aggregate responses of the 14 participants with Internet access for personal use are illustrated in figures to show trends of agreement or disagreement related to each UTAUT2 factor.

Performance expectancy. Overall, the majority of participants ($n = 9$, 64%) responded positively to all three UTAUT2 questions about performance expectancy. Six (43%) participants responded as undecided or disagreed with one or more of the performance expectancy questions. Participants who did not have access to the Internet at home and only accessed the Internet

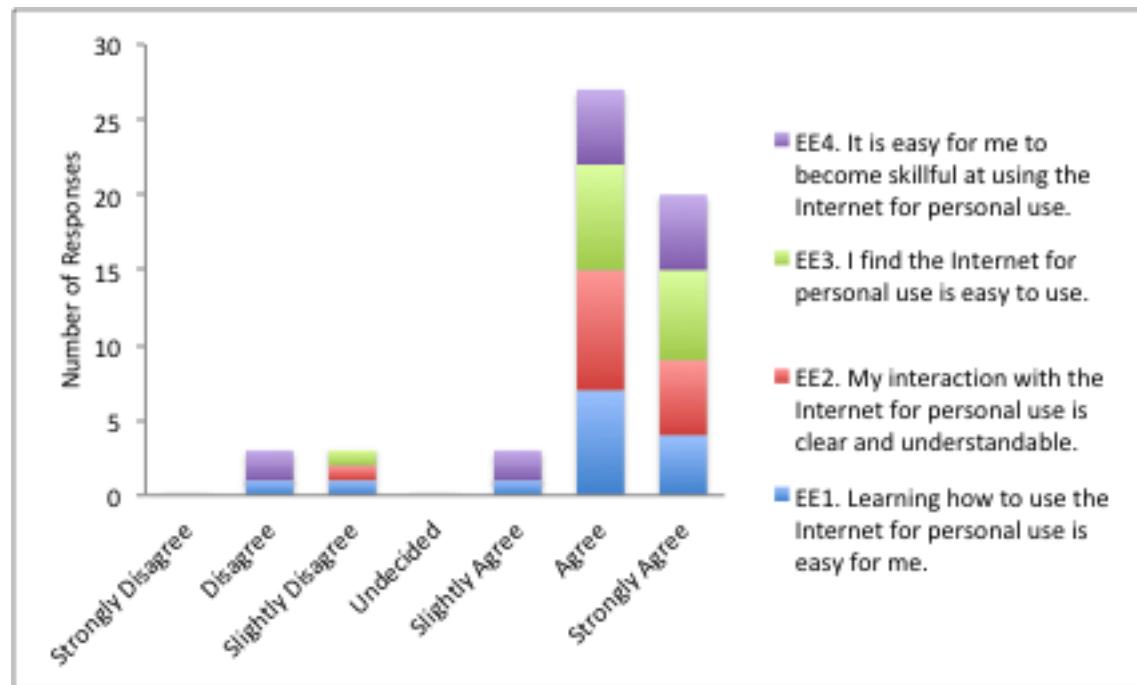
weekly or monthly ($n = 3$, 21%) tended to respond negatively to one or more questions about performance expectancy. Additionally, two older adult men who noted difficulties using the Internet, but used the Internet daily, also responded negatively or undecided with regards to performance expectancy.

Figure 1. Participant Responses to UTAUT2 Questions About Performance Expectancy



Effort expectancy. Effort expectancy refers to how easy the participant finds using the Internet for personal use (Venkatesh et al., 2012). Overall, the majority of the participants ($n = 11$, 79%) agreed to all four of the UTAUT2 questions about effort expectancy. Three (21%) participants disagreed with one or more of the effort expectancy questions. These participants were two older adult men and one adult woman, all who had a high school diploma or less schooling.

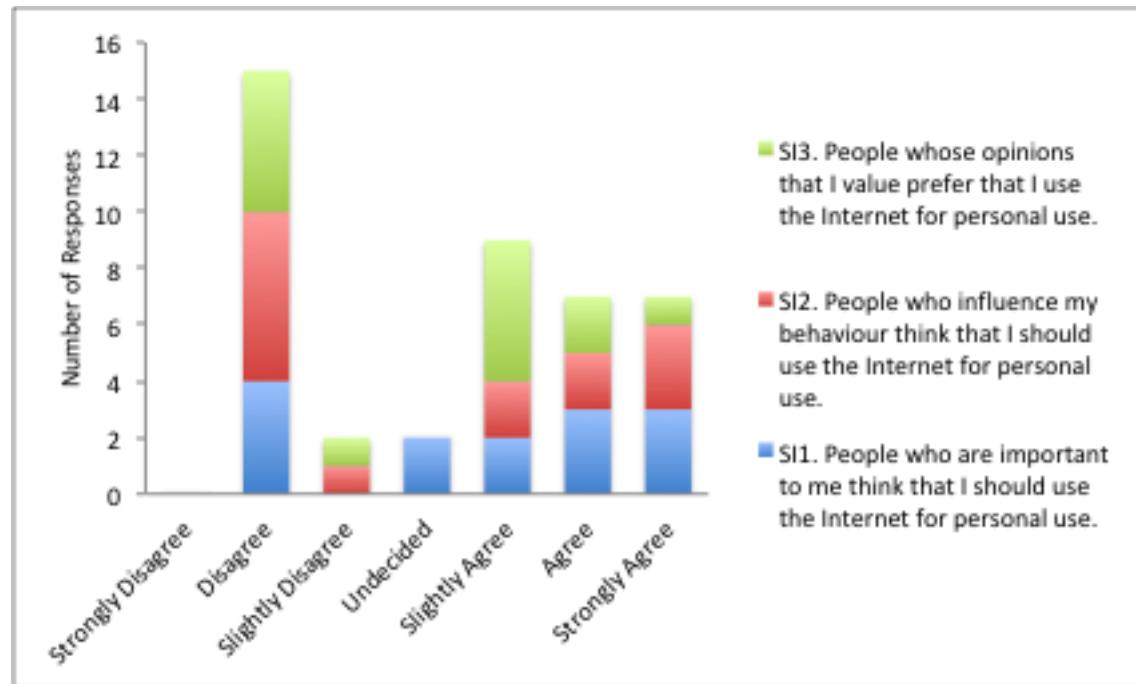
Figure 2. Participant Responses to UTAUT2 Questions About Effort Expectancy



Social influence. The majority of participants ($n = 8$, 57%), using the Internet disagreed or were undecided with regards to at least one of the three questions about social influence. In general, the participants who disagreed with the social influence questions commented that they disagreed because they felt they are not really influenced by others in this way; that they choose to use the Internet for themselves, not because others want them to use the Internet. For the

remaining six (43%) of participants who agreed with all three social influence questions, some commented that friends and family encourage and have an influence on their use of the Internet for personal use.

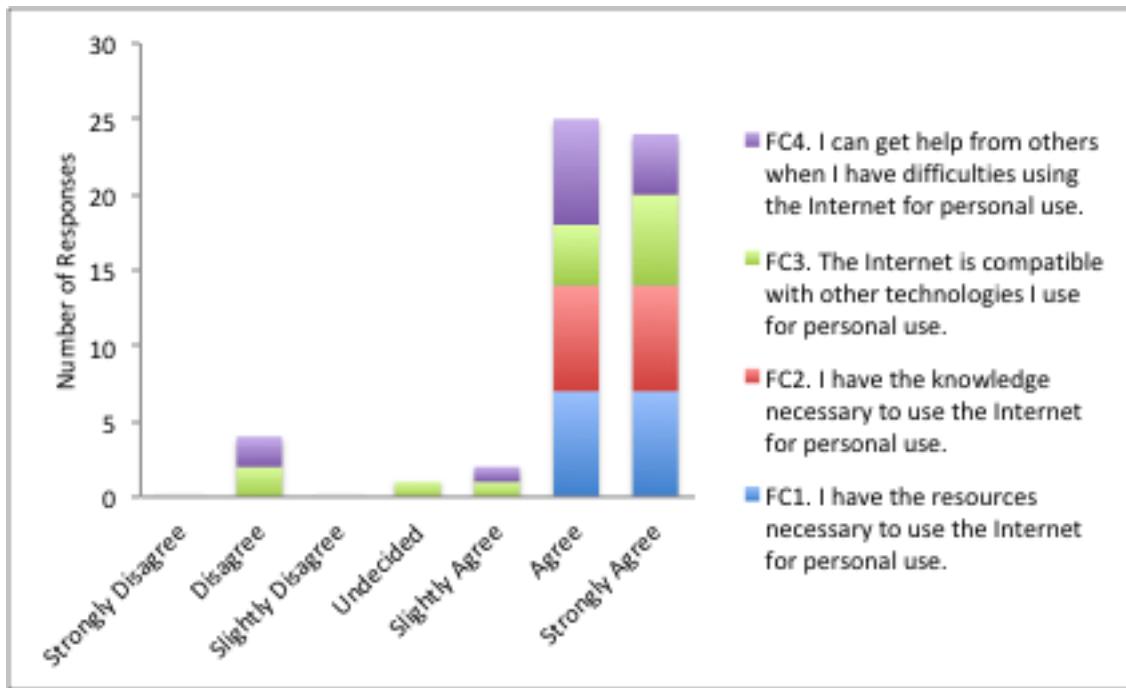
Figure 3. Participant Responses to UTAUT2 Questions About Social Influence



Facilitating conditions. All 14 (100%) of the participants using the Internet agreed that they had the resources and knowledge to use the Internet for personal use. Regarding having the necessary resources to use the Internet, one participant noted where they currently live the local infrastructure only allows for dial-up Internet service, so they have not bothered getting Internet access at home, and instead use faster dedicated connections at other locations. However, four (29%) participants disagreed or were undecided about the Internet being compatible with other technologies they use, and whether they could get help if they had difficulties using the Internet

for personal use. For example, one participant had a smartphone, but did not know if or how to use the smartphone to access the Internet.

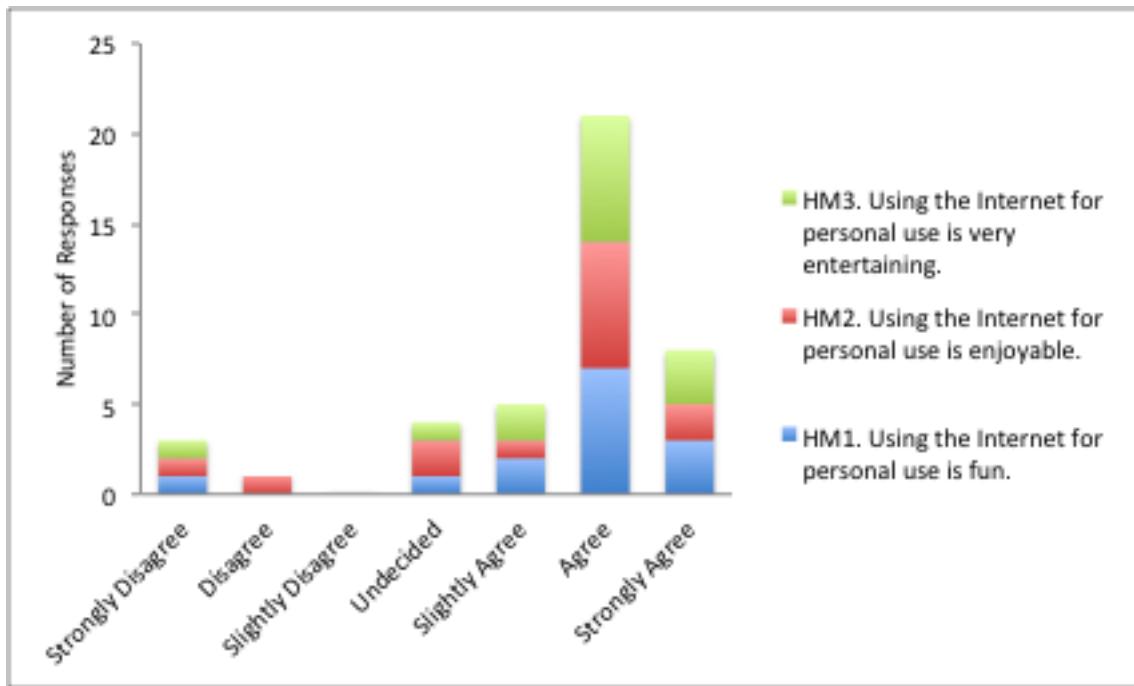
Figure 4. Participant Responses to UTAUT2 Questions About Facilitating Conditions



Hedonic motivation. Although the majority ($n = 10$, 71%) of participants using the Internet agreed with questions related to enjoyment of using the Internet for personal use, four (29%) disagreed or were undecided; these four participants also disagreed with performance expectancy questions. Two of the same participants also had difficulties with learning and using the Internet (effort expectancy questions). For these participants, it may be that difficulties with learning and using the Internet outweighs some benefits of the technology, and makes Internet use less entertaining. Conversely, participants who agreed with the questions commented they

mostly use the Internet for fun and sometimes spend too much time using the Internet for personal use because they find it entertaining.

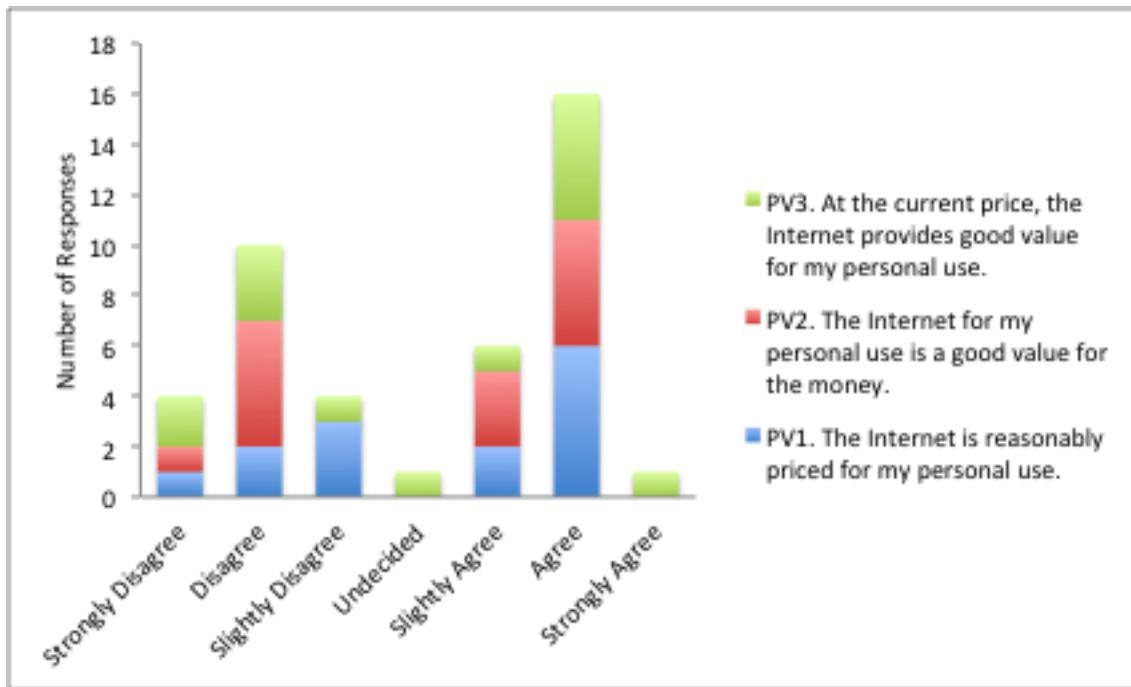
Figure 5. Participant Responses to UTAUT2 Questions About Hedonic Motivation



Price value. Similar to social influence, the majority of participants using the Internet ($n = 8, 57\%$) indicated they disagreed or were undecided about the price value of using the Internet for personal use. After answering the UTAUT2 questions about price value, participants who had Internet access ($n = 14$) were asked what they paid per month for Internet service. Eight (57%) of the 14 participants with Internet knew approximately how much they paid for Internet service each month. The average cost of Internet for the eight participants was \$70 per month ($SD = \20) with a minimum cost of \$55 per month and a maximum cost of \$110 per month. One participant said they did not know the price because they shared the cost with others. Although another participant was happy with the most affordable basic Internet service, another participant felt it

was expensive for slow service that does not include telephone service. Other participants felt the service was expensive given complaints about slow Internet speeds, interruptions, or poor service during poor weather conditions, with one participant describing the service as “lousy and cuts out anytime.” Conversely, another participant who also uses their home Internet service for a home-based business felt that it “pays for itself.”

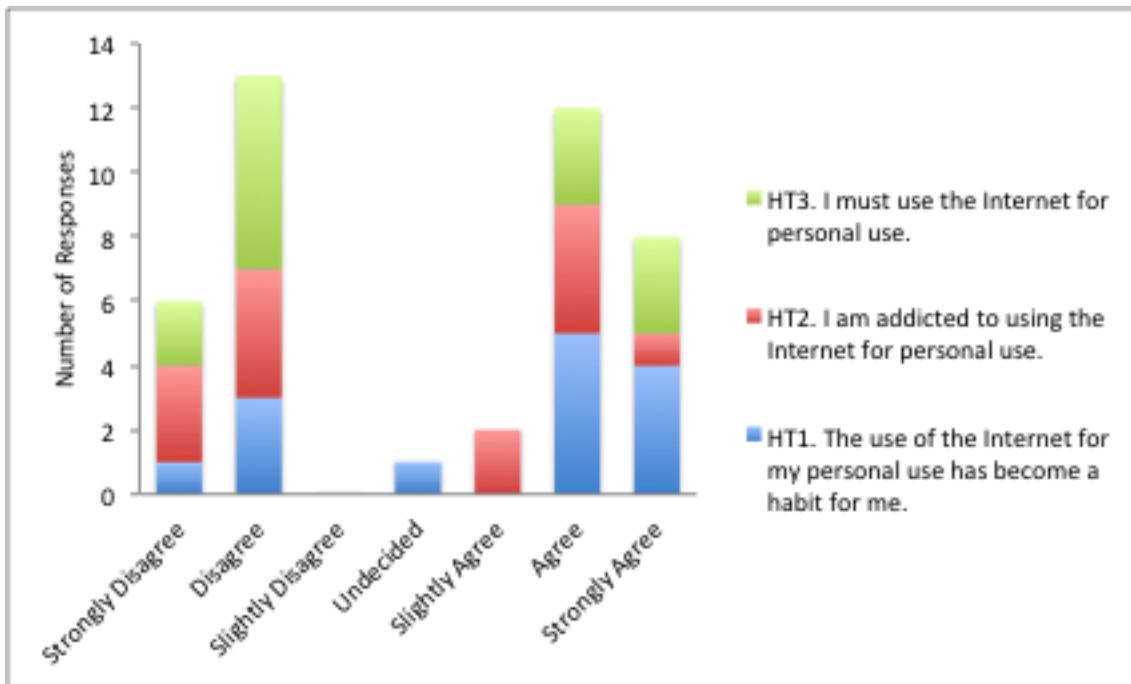
Figure 6. Participant Responses to UTAUT2 Questions About Price Value



Habit. The questions about habit were the most disagreed upon among the UTAUT2 factors. The majority of participants using the Internet ($n = 9/14$, 64%) disagreed or were undecided with one or more of the questions about their habitual personal use of the Internet. Most participants ($n = 9$, 64%) disagreed that they “must use the Internet for personal use,” and half (7, 50%) disagreed that they were “addicted to using the Internet for personal use.”

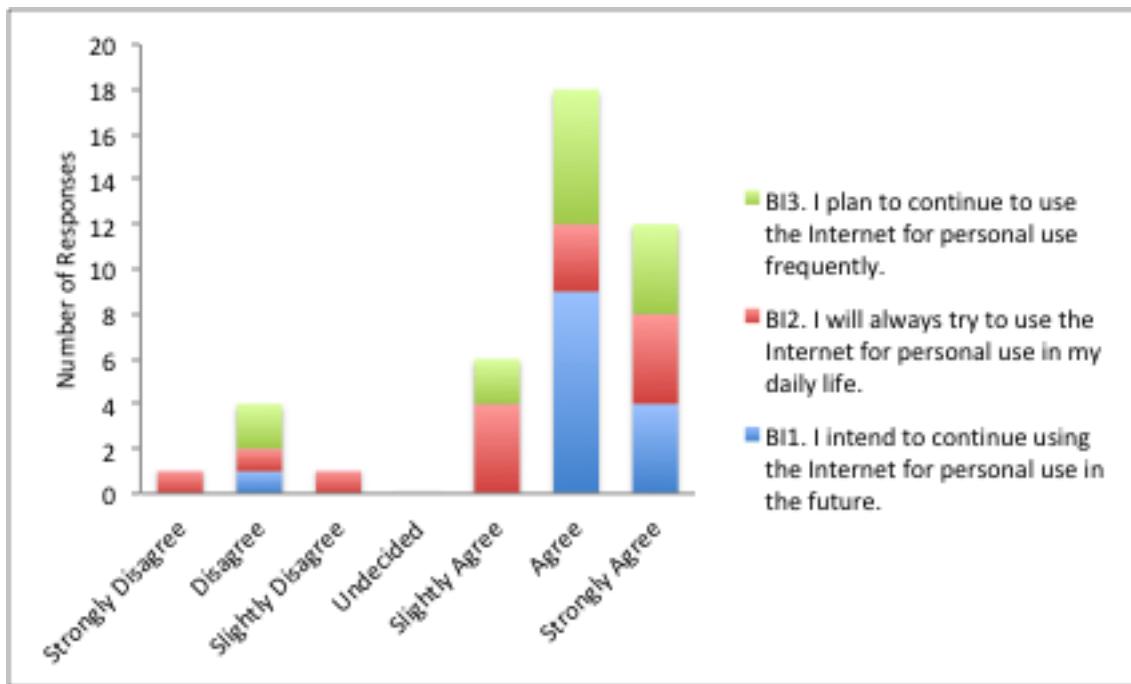
However, nine (64%) participants agreed “the Internet for my personal use has become a habit for me.”

Figure 7. Participant Responses to UTAUT2 Questions About Habit



Behavior intention. Responses to questions about continuing use of the Internet for personal use were generally positive. Ten (71%) of the 14 participants using the Internet agreed to all three questions, indicating intention to continue using the Internet for personal use. The remaining four (29%) disagreed with one or all of the three questions regarding behavioral intention, suggesting less likelihood of continued use of the Internet for personal use.

Figure 8. Participant Responses to UTAUT2 Questions About Behavior Intention



Participant comments. Other spontaneous participant comments were noted throughout the survey. One participant asked for clarification regarding some of the words used in the UTAUT2 survey and was provided with explanation by the interviewer. One participant stated that they were comfortable using telephone and Internet for recreation, but did not feel comfortable using either for health services as they do not trust the confidentiality and security of telephone and Internet. Another participant specified that they only used the Internet for personal email correspondence, and had no interest in using it for anything else. Conversely, another participant was open to the idea of accessing health services using ICTs like telephone and Internet, but admitted they would likely need some training beyond their current self-described “basic” Internet skills. Finally, after completing the UTAUT2 survey, one participant stated they wish there was a way to access peer support through text messaging or a smartphone app.

Quantitative Findings: Patterns of Demographics, PAM-13 Score, and Telephone and Internet Use

Participants without a telephone ($n = 3$, two women) were between 35 and 54 years old. Non-Internet users were all men ($n = 3$); two between 55 and 74, and one was between 35 and 54 years old. One adult man participant had neither telephone nor Internet for personal use. Participants without telephone or Internet all reported an annual income of \$19,999 a year or less, or did not know what their annual income was, and all received income assistance or disability benefits.

With regards to participants' access and use of telephone related to their PAM-13 activation level, no clear differences were noted. The three (18%) participants without telephones all scored level three for activation on the PAM-13, where participants who scored level two and level four for activation, all had access to a telephone. However, two out of the three participants without Internet access scored level two for activation on the PAM, the lowest scores of the sample. Table 8 shows average PAM-13 scores for participants with and without personal access to the Internet.

Table 8. Mean PAM-13® Scores for Participants With and Without Internet Access, $N = 17$

Access to the Internet for Personal Use	<i>n</i> (%)	Mean PAM-13 Score (<i>SD</i>)
Never	3 (18)	56.5 (4.7)
Monthly, Weekly or Daily	14 (82)	69.4 (8.3)
Total Sample	17 (100)	67.1 (9.2)

Note. Due to rounding, some totals may not correspond with the sum of separate figures.

Overall, there were no obvious patterns regarding participant characteristic of people who were more likely to agree to the questions on the UTAUT2 that contribute to predicting intention to use, and use of the Internet for personal use. Young adult participants, 18 – 34 years old, agreed with more than half of the factors used to predict Internet use; however there were only two young adults (14%) in the sample of participants who used the Internet ($n = 14$) and both adults and older adults were found to be both agreeable and disagreeable with more than half of the factors used in the UTAUT2.

Qualitative Findings: Prioritized Needs in Context

Participants were asked to prioritize their top three needs that they had identified during the interview. Some needs were intertwined and included more than one factor, for example the need to access HIV medications, and subsequent need for transportation to visit city-based health professionals. Common themes and subthemes shared by three or more participants are elaborated on in more detail. Less common prioritized needs are listed and briefly described at the end of the section. Participants commonly prioritized needs that they felt were essential for living with HIV in a rural area, or needs that were unmet at the time of interview. Participants identified priority needs that fell into four theme areas: (a) access to self-management resources, information and services; (b) education to reduce stigma; (c) access to peer support; and (d) transportation. Themes are ordered here according to the highest number of participants in the sample who noted a prioritized need within the larger theme. Themes and subthemes are described in context of barriers, resources and solutions that participants spoke about during semi-structured interviews, and include participant quotes. A commonly shared barrier that emerged from participant interviews was a lack of trust in local services, and is described in detail following the description of commonly prioritized needs. The letter “P” followed by a

randomly assigned number between 01 and 17 identifies participant quotes while protecting individual identities. Age classification and gender are also used to provide context to each quote. Participants aged 18 – 34 years have been classified as a *young adult*, 35 – 54 years as an *adult*, and 55 – 74 years as an *older adult*.

Access to self-management resources, information and services. Participants' commonly prioritized needs related to what they considered essential for self-management of their HIV and overall health. Subthemes of unmet needs were varied and included: (a) Consistent access to HIV medications; (b) access to a comprehensive information resource for people living with HIV in Manitoba; (c) self-management supports for healthy living in the context of living with HIV; (d) family or surrogate support; and (e) a safe place to live.

Consistent access to HIV medications: “My meds...that should be more important than anything else.” P05, adult woman. All participants considered regular, consistent access to their medications essential. Participants who received Employment and Income Assistance and/or Income Assistance for Persons with Disabilities had the cost of medications covered; however, participants who were not eligible for such benefits, and who did not have employee health benefits at work reported difficulty affording HIV medications. P17, a young adult woman illustrated this issue noting a recent period when she did not take medications for weeks, because she could not afford them. Even with a provincial subsidy program she said, “I’ve gotten a couple of loans [to pay for the medication subsidy program minimum] but I mean, I still have to pay that back and with interest.” Related to cost, P04, an older adult man with sufficient means to drive over 100 km to Winnipeg regularly, chose to purchase his HIV medication at a wholesale pharmacy only available in the city: “Well on my drugs from [name of wholesale pharmacy] was about \$700 overall cheaper...so when you look at every three months, \$700, so

who's making the money?" Interestingly, even participants who had their HIV medications covered at the time of the interview, worried enough about the expense of medications and possibility of losing coverage that many expressed the need for universal coverage for HIV medications.

P05, an adult woman, and P10, an older adult man, noted not being able to take medications sometimes when they run out, and are delayed being able to get a prescription refill in Winnipeg due to issues with arranging for transportation or weather preventing travel from their home community. P10 acknowledged that there were pharmacies closer to where he lived, but described not seeing those as an option due to concerns about maintaining privacy in his home community. P05 suggested:

Give [enough] meds maybe about an extra week or something, you know, because you don't, you're not going to predict the future what's going to happen...Like weather wise...again, transportation. Maybe you don't find the right person, or that person doesn't want to take you because they think you're too sick. So they don't take you. So you got to miss an appointment.

Comprehensive information resource about living with HIV in Manitoba. Based on their experiences, some participants wished for a comprehensive resource specific to managing living with HIV in Manitoba. The type of information that participants wanted to be included in a comprehensive resource was varied.

Health care, medical and scientific information. P03, an older adult man described what he felt was important to include in a comprehensive resource: "You've just been diagnosed, here is what you should know...Here's what's available...this [provincial health care subsidy] program...blood work...just sort of an online information kit." Participants spoke of wanting to

know the basics of when appointments need to happen, what happens during those appointments, information about medications and known side effects, facts about how the test for HIV works, and what results mean. Participants also spoke of wanting to know clear facts to assuage their fears of infecting others. P08, an older adult man said: “I didn’t have a full knowledge base...that I might infect [family members] inadvertently...if I have a nose bleed or something like that...[I] worried, just what if I cut myself around the house and being worried about that.” Some participants identified wanting a better understanding of scientific and medical terms to help them learn about HIV, effects on the body, and how research evidence might apply to them. Regarding the amount or depth of information available in a comprehensive resource, P17, a young adult woman spoke of the importance of having access to “just basic information where they can just click and get all the information. And if they want more details they can click on another link, get more info.” However, P17, and others say that besides practical information, the important message to hear when first diagnosed is, “it’s not the end of the world; you’ll get through this.”

Systemic benefits. Participants also mentioned wishing information was readily available to find out about tax benefits related to health expenses and living in a rural or remote area, such as knowing about eligibility to claim mileage to access medical services at a distance. One participant noted being confused about the implications of moving from disability to old age benefits and what their options were. Another need related to information about what to consider regarding insurance benefits and options while living with HIV. For example, one participant was frustrated with not being eligible for home mortgage insurance through their financial institution due to having disclosed their HIV status.

Aging with HIV. P04, an older adult man, wondered about living options as he ages, and if he'd be treated differently: "I don't know because of my illness if I'd be technically quarantined on a different, like ward or something...because I don't know what's out there for like people [living with HIV] even when they're seniors that are going to be in nursing homes."

Disclosure of HIV status. Some participants wanted information about disclosure at work. P14, an adult woman, was interested in a job that requires employees to have their blood tested: "If I have to go for training, I have to do blood work, and then I'm kind of threatened about that because they're going to find out [about my HIV status]." P04, an older adult man, who had disclosed HIV status to an employer and to healthcare workers in the past, wondered about what happens to disclosed information after the fact: "Now I don't know if it was put onto my personal file or if it was just put in the back of his mind." P04 wondered who in the health care system knows his HIV status; for example if disclosed to a family physician, does the receptionist know? Many participants mentioned being particularly concerned due to living in a small place where personal and work relationships may often overlap with those involved in providing health care services.

Information needs change over time. P07, an adult woman, said "It took me about I'd say 3 to 5 years to finally accept it and, deal with it [learning about her HIV diagnosis]."

Participants' questions arose with aging, training for a new job, or starting a new relationship. P08, an older adult man, needed to seek out information about starting a new intimate relationship years after being diagnosed with HIV: "But I have a girlfriend [now]...and I told [the doctor], you know, okay, how do I deal with this relationship now, right? And I didn't know that before because nobody offered me that information before." Some participant's spoke of the shock of being diagnosed while alone and in the city for the appointment, and not being able to

process information that may have been offered at the time of diagnosis. These participants noted that access to a comprehensive resource about living with HIV in Manitoba would offer an option for reliable information despite living somewhere with no HIV specific services.

Internet as a solution and a barrier. Although many participants pictured a comprehensive resource for living with HIV in Manitoba as an online resource, this format would pose a significant barrier for a few participants. The few participants without Internet access felt hampered in accessing information. P10, an older adult man, said: “But if I could get Internet, that would be a big thing...” P10 specifically was interested in using the Internet to access up to date information about HIV and stay connected with the HIV community like he did when he lived in Winnipeg. Reasons participants gave for not having Internet were primarily that it was too expensive; all participants without Internet were receiving income assistance, disability or pension benefits. Participants without Internet access also acknowledge they would need some support to learn how to use the Internet. P13, an adult man said, “Computer training. Like I want to, I’m missing out a lot on the Internet.”

Self-management supports for healthy living. Participants spoke about focusing on overall healthy living as a way to manage their HIV. P07, an adult woman said: “The only thing I can do is try to maintain my health and eat properly, sleep, and take my meds.” P09, an adult man agreed that this was his focus for rehabilitation from significant illness related to HIV diagnosis, as well as getting back to a regular exercise routine. Healthy eating, safe weight loss, time management, and exercise were noted as important factors that contributed to participants being in control of their health in the context of living with HIV.

Participants who noted needs related to support for healthy eating in the context of HIV were from all age categories. P02, a young adult woman notes, “I know how to cook. It’s just I

don't always cook healthy." P13, an adult man wondered if having some one-on-one cooking support might help with his goals to eat healthier: "Maybe I need somebody to come cook with me...like a person to come cook for me the healthy way. I have a lack of cooking, I just cook something simple...like heat and serve." Adult and older adult participants specified needing to manage healthy eating and weight related to challenges of side effects they believed to be linked with HIV and treatments, such as metabolic disorder, lipodystrophy, high cholesterol and high blood pressure, or other co-morbid conditions like diabetes. P04, an older adult man says, "Only problem is I can't control, I keep, I'm supposed to lose weight and I can't lose weight." One participant described having tried several diets in the past, including one that included an herbal supplement that interacted with HIV medications and led to high blood pressure. Another participant who was approaching retirement and noted being overweight wondered if leaving their physically active job would negatively impact their weight, and recognized a potential future need to change daily routines to include more recreational exercise to stay healthy.

For some participants with lower income, the cost of and access to affordable, healthy food in their community was a challenge. Some participants described accessing a food bank when in Winnipeg, but not having, or not wanting to access, to a similar service in their community for privacy reasons. Participants like P10, an older adult man, and P13, an adult man, looked for opportunities to supplement their groceries with hunting and fishing. Conversely, some participants struggled with lack of appetite, and low weight related to side effects of HIV and or medications. Several participants reported difficulties with eating related to nausea, vomiting, diarrhea and lack of appetite.

Finally, two participants indicated a need for learning time management skills, particularly around scheduling health appointments and travel to the city, school, family and self-

care responsibilities. P03, an older adult man explains, “Because when you first step into the [HIV] world, it’s just very confusing...because it alters you completely. Because what happens is...I mean, your whole life then becomes, you have to build it around [your health condition].”

Family or surrogate support. Many participants spoke about how family support plays a large role in managing their health, and how participants without sufficient family support may find it harder to access services while living in rural areas compared to a metropolitan centre. P03, an older adult man said:

Family may be the same in Winnipeg as outside Winnipeg...but if someone in Winnipeg didn’t have family and someone in [small rural town] didn’t have family, I would think the person in Winnipeg would be better off. There’d be more support systems built into the social fabric that’s available in Winnipeg...So I think that would be very difficult...How that’s addressed, I don’t know. So, yea, family would be number one, like the support system they have. Not so much the medical support, but the day-to-day living support.

P03 described depending on family not just for moral support, but also for a place to live, help with food preparation, and transportation related to managing his health condition. P12, an adult woman, also described the support from “My friends and my family” as the most important support for managing her day-to-day health, and like others, described learning about and how to manage daily health together with family. For many participants, family provided emotional, physical and financial support like a place to live or stay, help with meals, reminders to take medications, transportation and more. For others, family was a source of stress or non-support, requiring other supports to replace that role. P17, a young adult woman said:

Because I mean family and friends are brutal. They're mean, you know. If you have an outside support, like either an accountability partner, or just a support partner, other than your family or friends in your inner circle, I think that would be a lot easier.

Some participants described having an “HIV family” through contact at a centre specializing in HIV prevention and care located in Winnipeg, despite having to travel to access the centre. P10, an older adult man who used to live in Winnipeg when he was first diagnosed, but now lives in a rural area says:

I remember the first year and that like it was like, uh, scary, like very scary. And I wasn't sure what; and then I learnt from others and learned from [HIV care centre in Winnipeg], stuff like that. And, then being out here is, like I said, you don't have the access like you do dropping in there every once a month, once a week...

P04, an older adult man felt that people without family support need targeted support: “There [are] people...who don't have the support from the family, and those are the people that you have to work with.” P08, an older adult man, describes his solution for building family support:

But see, with us it was my family all learnt with me, right. That's the strength we have...but other families don't have that...[you need to connect] somebody that's part of their extended family...you need to break through that...[and develop] that close relationship and then to build that trust to the extended [family]. And it usually just starts with one [family member].

P17, a young adult woman, describes the need for services that can help educate the family and friends of people recently diagnosed with HIV.

I think if there's a support system, not only with the people that are living with HIV, but the families and friends surrounding that person, if they can have a workshop or

something for them to understand...What can you, how can you be supportive of somebody living with HIV as opposed to making them feel, um, segregated...

Safe place to live. A few participants identified the need for a safe place to live, at the time of interview, in the past, or when travelling to the city for health related appointments. P13, an adult man, described not always having a safe place to stay in his home community, but having been on a waiting list for subsidized housing in a nearby, larger community for over three years. He spoke of struggling to manage his health and get sufficient sleep while living out of three different places, and hoped to be delayed when in the city for appointments so he could stay at a medical boarding house and get a good sleep. Conversely, P05, an adult woman, had difficulty finding a safe place to stay when she is in the city, noting where she stays has a lot of “people going in and out, people having a drink inside the house.” P14, an adult woman, expressed experiencing challenges trying to move from living on a reserve to the city, for better access to health services for herself and a family member with another chronic episodic health condition. “And you have to explain [where you’re from] because they do a credit check. It’s so complicating.” P14 explained not having a credit history for renting due to living in reserve housing in her home community. P14 wished there were alternative housing options that she might move into in the city, such as a supportive housing option for women living with HIV:

I wish there was more housing...how come there's not for women who are HIV? Even for women who are getting their kids back...And then some of us don't have family [support]...I wish they'd give us an old abandoned building and then can fix it up and make our own little apartments so we all know, know each other.

Alternatively, some participants felt that living in a rural area had improved their health and ability to self-manage living with HIV. P06, an adult man said: “Well actually it’s a positive

for me to move out of Winnipeg...I would have had a more of a harder time [there].” He described difficulties with having belongings stolen from him in the city, versus being able to affordably work out of his home and live peacefully in the rural area he now lives. P10, an older adult man agreed:

I live by myself in a little town. And, I kind of do what I want. I work a bit. I do nothing sometimes. And just have fun. Enjoy. And nobody knows really out here [about my HIV status], and I don’t really hear about it [HIV] out here in [town]. And I’m healthier out here, than the city. Yea, I like it out here.

P10 described struggling in Winnipeg with: “unemployment, the violence, the drugs...[living] on disability or welfare...and your living conditions are [in the city], life is shitty.” Even though he reported difficulties with transportation to access health services in the city, and felt out of touch with the HIV community, P10 felt that living in “the country” had improved his health and quality of life.

Education to reduce stigma and misconceptions about HIV. Participant perceptions and experiences of HIV stigma were closely intertwined with prioritized needs and barriers; for example, experiencing a lack of family support, not having a safe place to live, and not trusting local services. Participants perceived a lack of knowledge about HIV in the general public where they lived, as well as among health and social service providers, as key issues leading HIV stigma experiences.

Educate people living in rural areas about HIV: “In terms of services coming to rural Manitoba...I think what we need first of all is a generally broad public awareness educational campaign.” P01, an adult man. Most participants spoke of a general lack of understanding about HIV where they lived. P17, a young adult woman wished that, “people understand that just

because someone has HIV, it's not a death sentence... You don't have to put the town on lockdown or something like that. It's just, I mean this is how bad it is in [name of community]."

Many felt their community was particularly behind the times when compared to larger metropolitan areas or even other places they had previously lived. P16, an older adult man said: "People still have an idea, you know, just by touching, or shaking hands [that you can get HIV]. And especially [in rural region] here, it's a state that's really is harsh you know...because it's the lack of information." P14, an adult woman described her experience of stigma due to living with HIV: "You get disowned from your own people and then it's kind of hard living on the outside of society, and it's really, really hard." Participants spoke of social and cultural factors that they felt influenced this lack of understanding, such as reluctance to speak openly about sex, bias against people related to their sexual orientation, gender, racism, use of intravenous drugs, and the past and current ways that HIV has been represented in the media. P08, an older adult man, described some of the misconceptions he's observed about young people learning about sex and HIV:

It's an issue they snicker at you know. It's like, "I went through the motions [of learning about HIV], you know, I don't need to believe it. I don't need to understand it." That's just the way that these young people, they don't see. They think because they're heterosexual, they can't get HIV, no matter how many times you tell them that, you know...And the one scary thing I heard from one group was, "well, people aren't dying of it now."

Although people living with HIV can now have a near normal life expectancy, P08's concern was that the message being heard is that HIV is something that young people no longer have to worry about prevention.

Several participants voiced not liking how HIV has been portrayed in the media with a focus on risk factors like being Indigenous, gay or an intravenous drug user. A few participants spoke specifically about bias toward people who are gay in rural areas. P01, an adult man says, “Whether you know someone’s gay, straight, bisexual, transgendered. There’s still [barriers], let’s just say the road here is not paved; it’s a dirt road.” P08, an older adult man described people not agreeing to HIV testing, avoiding seeking information about HIV, and not disclosing their HIV status to qualify for services in small communities, due to fear of being identified as gay, regardless if they are gay or not. P08 also felt the way HIV is portrayed in the media furthers a racial divide where he lives:

I hear those words being said by white people about the communities. I see that. That’s part of the problem as well. [I: What do you hear them saying?] Well, “you gotta be careful of the Indians, they’re HIV.” They say things like that. Typical, derogatory things that they say because they hear it in the media you know. They see the numbers on T.V. Some participants voiced that connecting labels like gay, Indigenous and drug user to HIV misconstrues the important message that HIV can, and does, affect everyone, regardless of sexual orientation, ethnicity, gender or drug use.

Participants felt the answer to broadly educate the public is to start by teaching young people in school. P07, an adult woman said: “People need to be educated at schools for one. Big time in schools. Like talking, starting in grade five, people speaking or just even the teachers teaching their students about, you know, HIV 101 kind of thing.” P04, an older adult man agreed that the best place to start is to educate children about acceptance and tolerance of differences: “And you tell the kids then, and they understand. It’s the ones who don’t understand are the parents.” P17, a young adult woman, felt that sex education in high school needs to be more

fulsome to include facts about HIV and other sexually transmitted infections and sexually transmissible and blood-borne infections: “Like, they have their sex [education] or whatever but they don’t, they take it very lightly. They don’t take it seriously in my perspective.”

Educate health and social services workers: “Because in little towns, health care providers aren’t up to date, really, on certain things and my opinion is, that HIV for one, they need to be more updated on stuff and how to diagnose a person’s needs, medical needs.” P07, an adult woman. P07 was not alone in feeling a lack of trust in rural health providers’ knowledge about HIV. P06, an adult man, spoke about his experience with a local, locum health provider prior to choosing to travel to Winnipeg where he finally received a diagnosis of HIV. He described being given medication that made his illness worse, and when it didn’t work, felt the health provider asked him to try another drug without any further testing. P15, an older adult man, added: “Well, you know, I said, the [locum] doctors really lacked information about HIV. Doctor [HIV specialist’s name in Winnipeg] gave me all the information about, information about HIV.” P08, an older adult man, offered a different perspective:

Sadly, the way we’re [set up], the medical professionals that are circulating in the rural areas, are so overwhelmed they can’t deal with the individual. So what ends up happening is that part of the partnership that should be there is broken. That trust is broken.

Another participant felt that social services workers should also be educated about the facts related to living with HIV. P14, an adult woman, described an interaction with a child and family services worker when she was first diagnosed:

And I remember one CFS worker came up to me. [They were] already making my, [they were] already making my death plan. Telling me, “Okay, what’s going to happen when

you die?" Like [chuckle] you know. I looked at [them]. I says, "What are you talking about?" [They were] like, "Well how do you want to go?" [they] says. "Well the kids, we have to make this plan." [They were] already making a plan for my funeral. I kind of looked at [them], it's like you're supposed to be my social worker, why are you making [my death plan]? And I said, Where did you get this from? [They] says, "Oh, somebody told me that you're dying." It's like, so I have HIV and then I'm dying.

P14 felt that assuming someone living with HIV would be dying was based on poor education about living with HIV. P14 also felt that lack of education about HIV led to children of mothers living with HIV being unnecessarily taken away and placed in care.

Because a lot of my friends that are HIV, all their kids got taken away. Because when the social workers found out they were HIV, all their kids got taken away. There is no questions asked. It's pretty much like, um, how would you say? We were infected and nursing like, that was the word they used. I guess [they thought] we were a threat to our kids. So a lot of us lost our kids because of it. It's not only me, but there's other ones.

P14 felt if child and family service workers and the legal system were better educated about HIV at the time when she was diagnosed, mothers living with HIV could have been supported to learn how to care for their children and receive the needed supports to ensure their children are not at risk. She described how her HIV had been brought up in court related to custody of her children:

And [the lawyer] goes like, "Oh, what if [participant's name] cuts herself and then the babies come there", and all that. Like [they] made like a big thing [of it]. And like, "how is she going to cover herself? She doesn't have first aid", and I was like, I could have got a first aid. I could have went to CPR, you know. I could did all that. If they ask me to, I

would have did it. But the way that lawyer put it, made me sound like really, really horrible, although [the lawyer] doesn't care...and it's like that is totally wrong.

P05, an adult woman, felt that the people who arrange medical transportation services, including drivers in her community, are not educated about HIV facts, which leads to her not having reliable transportation to Winnipeg. P05 explained that she has been bumped from getting medical transportation to Winnipeg at times when other people are also needing to travel at the same time, and she felt it was related to her HIV status and medical transport personnel misunderstanding the risks of her travelling with other people who are sick.

Several participants felt that health care agencies were responsible for the message about HIV that is portrayed to the public. Participants spoke about health agencies needing to educate the public with a re-envisioned HIV of today, versus what people remember from the 1980s when awareness of the disease came to North America. P04, an older adult man, said:

The thing is, society, a lot of society thinks "oh, you have HIV, I can't touch you actually", or "I'm going to get it from you." But no you can't...But it's to educate the people, because they've seen the worst of like, like Rock Hudson and a few other people that died of it...so that's what they remember.

P01, an adult man, said, "I think someday...HIV will become a respectable disease, if a disease can be called respectable. You know such as cancer, for example. If someone gets a diagnosis of cancer, then most people aren't chastising or looking down on them..." Participants, like P01, felt that the message about HIV in the media needs to change: "Who is affected by HIV? Everyone." P08, an older adult man, argued that a change in approach to informing people about HIV is key: "People aren't dealing with HIV as a disease. They're dealing with it as a lifestyle issue and that's not where that should be." P08 felt strongly that if health care professionals

refocus education about HIV as a disease that can affect everyone, and get away from focusing on the risk factors, this may end the trend he reported observing of people being judged or blamed because of stigma associated with sexual orientation, drug use, or ethnicity.

With regard to educating health care providers in rural areas, P08, an older adult man, explained that a partnership between visiting health providers needs to be made with local health providers in the community in order to understand each community's needs and dynamics. Without this understanding and partnership, efforts to test for and prevent HIV will not work, in his opinion. He explained, "That's very, very important about this. And it has to be dealt with from a disease perspective, not as to how you got it or a lifestyle issue." P08's reference to lifestyle issues was to risk factors for HIV like sexual orientation or drug use. He explained his perspective that highlighting these risk factors and asking people about risk factors discourages people from getting tested, because they feel that HIV does not apply to them, or that they do not want to be associated with these risk factors in their community. He described a person in his community who initially declined an HIV test despite being offered one at the local health centre; after speaking with P08, the person went back to do the test and was positive for HIV.

P07, an adult woman, described the qualities of a health care provider that helped her in her journey living with HIV:

[They] were somebody I could talk to and confide in, and [they] really opened my eyes to a lot of things about being infected and, yea, that's how I learned mostly everything was just talking with [them]...[I: What were the qualities that made [them] a good person to work with?] Just [their] demeanor. Like just the way, [their] character. [They] were very friendly and like totally non-judgmental, and you know, [they] were just, was accepting.

Access to peer support. Many participants prioritized an unmet need related to accessing peer support opportunities from where they live, and needing the chance to interact with others who are also HIV positive. Having access to private, confidential, and safe peer support was identified as most important at diagnosis, but not available where participants lived. Peer support was also noted as an unmet need for people who have been living with HIV for years, but would like to connect with others who are living with HIV, or would like the opportunity to support others by sharing their experiences living with HIV.

Peer support at diagnosis: “And then when you see the new people [just diagnosed with HIV] I’m crying because I was like that too. And I wished someone could talk to me. I wish somebody would just come up and to say...you’re going to be okay. But nobody did.” P05, an adult woman. Participants often wished they had connected with another person who was similar to them, and who was living with HIV when they were first diagnosed. P17, a young adult woman remembered:

Because like when I first got diagnosed, I thought it was the end of the world...I didn’t want to touch anything, anyone, see anyone, talk to anyone or be around anyone. But it’s just like if somebody [living with HIV] gave me that information saying, “hey, this is your diagnosis but don’t worry, it’s not the end of the world...Your life will change...but it’s going to be okay.” And I never received that when I first got diagnosed.

Some participants, although living in rural areas at the time of the study, were living in Winnipeg when they were diagnosed and spoke of the importance of having a connection with other people living with HIV. P10, an older adult man spoke about how he learned to live with HIV from interacting with peers at a community health centre in Winnipeg:

I learn off other people, a lot of learning off the other [people living with HIV]...You gotta talk to these people, you know, I had only been positive two years and they were positive like eight years on. Just listening to them talk, [learning about] my blood counts, and this and that, every little bit of information is important...that gave me the HIV skills to live with HIV.

P10 admitted he did not know where a person newly diagnosed with HIV could go for peer support in his community, “being out here is, like I said, you don’t have the access like you do [in Winnipeg]...if I was told here I had HIV, it would be completely different. I don’t know how I would have dealt with it.” None of the study participants were aware of any HIV peer support options in their community. Some participants attended peer support groups in Winnipeg when they were in the city for other reasons. P14, an adult woman said:

But there’s none, not like Winnipeg, they have programs where other women who are [living with HIV] you know, where you can go and talk...It’s not like back at home, like when you go there...you’re living on your own you know.

Peer support beyond diagnosis: “Well, I kind of miss the [peer support program] thing.” P10, an older adult man. Despite having lived with HIV for years, many participants spoke of an unmet need of having access to peer support where they lived. P01, an adult man, like P10, enjoys living in a rural community but missed being connected with other people living with HIV:

I do like it here. It does have its pluses and minuses. But it might as well be in [remote location] in terms of feeling isolated and not having a connection to, you know, say a [peer] support network now.

P16, an older adult man, described why he would attend a peer support group if one was available where he lived:

Because you know, sometimes it plays with your mind and you know it's good to have, you know, to be with and talk with people who have the same problems and, you know. You bounce different ideas off the wall and get support.

Opportunity to support others: “You might not need the support but you give the support because you’re helping other people [living with HIV] that might need support.” P04, an older adult man. Not only did participants identify needing ongoing access to peer support, but some participants also spoke of needing an opportunity to support others living with HIV.

P17, a young adult woman, described why she would like to participate in providing peer support: “I mean, it would be nice, because even for like people who are just recently diagnosed, at least we can pass on like our experiences and knowledge and say, ‘hey, don’t worry about it, you’ll survive’.” P14, an adult woman also described a strong desire to help others who are living with HIV in her community and other small rural communities:

I want to be an advocate for people who, who are HIV [positive] or just getting...being diagnosed. Especially the young ones, who are like mothers and they don’t know where to go. They’re all scared. And there’s so many of them. Like they’re all trapped in a house and then they’re all scared to come out. There’s lots of them.

Regarding any kind of peer support solution, all participants agreed that privacy and confidentiality are key considerations that are especially important in a rural community. P01, an adult man said:

I would like...to be able to access services in a respectful yet discrete manner. Like you don’t have to do it, you know, in shame...I’m not at that point right now for disclosure

because, you know what my bias is...if people in this town hear you are HIV, they'd burn your house down.

Several participants responded negatively when asked if they would attend an HIV specific service in their community. P12, an adult female said, "No, because it's rural and I like to keep it hush-hush." P10, an older adult man who noted an unmet need of connecting with peers also said, "...if it was out here [in rural area], like if there was a meeting every month or something HIV, I probably wouldn't go."

In part due to this concern about privacy, participants described having a peer support network that could be accessed by telephone, cellular phone text messaging or an online forum. P14, an adult woman, suggested an "app" so people with HIV could talk privately with someone who has lived experience. P16, an older adult man offered "a website or telephone number that somebody can call." P17, a young adult woman said it would be beneficial to have exclusive access to an online group when diagnosed:

If you're interested, you can get an access code to go into the support group or you can contact real people with real names that have, you know, that are living [with HIV]. And that way if they're not diagnosed, then, you know they don't get that [access code].

Participants also described a peer support program that could be accessed at a distance to address the fact that people living with HIV in rural areas are often widely spread out from each other and transportation can be a barrier. P16, an older adult man said:

Yes, that [services via telephone and Internet] may be good, because you know, it's, everything is so spaced off around here...and I don't really know the amount of people that's affected in this area or anything. I have no, no idea.

Despite many participants being open to accessing peer support using telephone or Internet, there were participants who preferred to access services face-to-face or who did not have access to a private telephone or Internet. P07, an adult woman had concerns about privacy: “For me personally I wouldn’t, I don’t believe I would ever access health information over the phone, or the Internet, because it’s so many ways people can scam, and like getting to people’s stuff on the computer.” P08, an older adult man who also preferred face-to-face services, described a small-scale solution for peer support:

And then I did create kind of a, our own little support group, that we meet privately...outside of our community...it was a [person living with HIV] that came and asked me if I would facilitate that for them. I said, yes, absolutely. So there's nine of us...[they] want to keep it [HIV] a secret...we meet at different houses...I understand their fear; I do, I really do.

Transportation. Access to affordable, reliable transportation when needed was reported as an unmet need for many participants, specifically those with lower income, no personal vehicle or those without a driver’s license. Additionally, even some participants, with higher income and their own vehicle, had difficulties related to transportation around the time and energy involved in long drives or flying, especially when not feeling well, or having to manage co-morbid health conditions. Like stigma, the unmet need of transportation intertwined with other unmet needs, like consistent access to medications, accessing peer support, and accessing other health services not available in home communities.

Access to transportation: “I would say more transportation, because a lot of us that come to the doctors, it’s like, it’s hard for us to find transportation.” P14, an adult woman.

P14 described not always being eligible for paid medical transportation from her community to

Winnipeg, or the restrictions of when medical transport was available not always meeting her needs. For example, she may not be eligible for medical transportation if wanting to attend a peer support meeting only available in Winnipeg, or if she wanted a family member to accompany her. P14 described medical transportation timing, “So you come in whatever, whoever’s coming in; they all try to make it like in one run.” This means she may need to spend an extended time in the city waiting for her appointment time if someone else in the community needs to come in earlier. P05, an adult woman, agreed that transportation to and from Winnipeg was the second most import unmet need for her. Participants described looking for people in the community who are driving to Winnipeg, or using local driving services, and needing to pay out of pocket, which can be a lot of money for participants whose main source of income comes from funded benefit programs such as income assistance or disability. P10, an older adult man, described his difficulty with transportation from where he lives:

I have a little hard time getting in and out because I don’t have a driver’s license...I go get my meds, and I do that in the city, and see my doctor in the city. Everything’s really in the city...That’s kind of hard to do sometimes because I have to get somebody to drive me. And I don’t really know that many people, like in [community name] here, I don’t really talk to anybody.

For a few participants, recovery from severe illness, often requiring hospitalization in the context of their HIV, required a focus on regaining functional mobility and independence with basic self-care tasks like toileting and bathing. Once discharged home, getting to and from appointments can become a challenge. For P11, an adult woman, this meant being dependent on others for transportation, as she was not able to drive. A couple of participants who lived close

enough to Winnipeg accessed subsidized or free services like Handi-Transit or rides provided by volunteers to get to health care appointments.

Service issues related to transportation: “Everything seems to be city centric; if it isn’t in Winnipeg, it doesn’t really exist.” P01, an adult man. Some participants shared their perspective of specific service issues related to living with HIV that were impacted by living at a distance from specialized services and available transportation. P03, an older adult man described not being able to access certain booster shots recommended for people living with HIV without travelling to Winnipeg:

There’s a bit of a two tier health system in a sense that, there are, in my case with HIV, there are two booster shots for pneumonia...that if I were living in Winnipeg I would get, automatically get them at the clinic. But here, I can’t get them...it’s I guess that their thing was “well that is not in our budget, we can’t give you those vaccines.”

P02, a young adult woman, chose affordable transportation as one of her top priorities, and noted another transportation service issue in her context of living outside of Winnipeg and receiving income assistance benefits.

That’s the hard side is the bus, because it cost so much to get from [home community] to Winnipeg...At least social assistance won’t help out because there’s doctors in [home community] and it’s my choice to go to [HIV specialist in Winnipeg].

P02 described why she chooses to see the HIV specialist in Winnipeg after a negative experience she had previously with a local health provider:

I was seeing a regular doctor [in home community], but then when I realized regular doctors, they don’t know a lot about [HIV] because I ended up in the hospital... and I didn’t have my meds on me, and the doctor ended up for almost a week giving me the

wrong meds. So...I don't really trust any other doctor other than my own [HIV specialist in Winnipeg] now.

Another service issue challenge that participants reported related to transportation of blood work samples for analysis. P01, an adult man and P16, an older adult man both described issues with not being able to get HIV blood work results consistently from where they lived. P01 noted the stress and frustration of attending regularly and on time for blood work in his community, only to have the sample often determined not useable due to "sitting too long" or being "improperly handled" prior to being analysed. This resulted in additional burden of having to attend for more lab appointments than necessary, and additional uncertainty about not having confirmation that ongoing HAART is successfully suppressing viral load. P16, an older adult man, described:

Because even right here in [home community], sometime I, like even the last set of blood I took, they didn't, the last two sets I took, they weren't able to get my viral loads because they sent it too late or they didn't, you know, I guess ship it properly.

P08, an older adult man, described his challenges with getting to multiple appointments, for multiple health conditions, in multiple communities:

And then of course, again, travelling to [four urban centres in the province] for like occupational therapy, that kind of thing. It's hard; it's hard. And some people don't see. They have a plan, like therapists, particularly in my case, where they wanted me to go to [urban centre] three times a week to go exercise...you know, there didn't seem to be any consideration for my ability to travel back and forth. [Medical services] transportation [from home community] is pretty good...[but] the time and the energy it takes to go over there.

P08, an older adult man, and P01, an adult man, both spoke of choosing not to drive their personal vehicles and take commercial or subsidized medical transportation to conserve energy when having to travel for appointments, especially in the winter. Additionally, P08 discussed how he wished all his care providers could better coordinate appointments to reduce the amount he needed to travel.

The few participants using Telehealth appreciated how it limited their need to travel to the city, but acknowledged it is only recommended when their HIV is well controlled and not requiring further assessment or intervention. One participant noted he would prefer eliminating his Telehealth appointments and receiving his blood work results by email as long as his HIV is well controlled as it was at the time of interviewing. More than half ($n = 9/17$, 53%), of participants were open to using telephone or Internet to access HIV related services to help reduce the need to travel to the city.

Some participants wanted more rural services in their community to reduce the need for transportation. The services most mentioned were having a local HIV specialist, or a primary care physician with training in HIV care, and access to some sort of discrete, HIV specific peer support or counseling program. Community centres were chosen by participants as appropriate local places to hold face-to-face support or counseling programs as they were discrete enough that attending would not identify them specifically as living with HIV, and that they typically had rooms with sufficient privacy for meetings. Participants generally said that they would like services to be provided by both peers living with HIV and health care providers knowledgeable about HIV.

Common barrier impacting needs: Lack of trust in local services and supports: “You just got to watch out who you talk to.” P05, an adult woman. Lack of trust in local health

services was a common concern. Many participants avoided getting health care services at local clinics or pharmacies as they felt the physical environment, workers, and other members of the public using the service put their privacy at risk. Regarding the physical environment, P01, an adult male, noted: “but [the clerks are] all, you know, facing the waiting room and there’s basically zero confidentiality.” He also described experiencing health workers providing confidential test results in open areas, where he often knows people in the waiting room who are within earshot. P04, an older adult man stated:

I don’t get my medication at the local pharmacy...it’s tough in a small community because I know dealing with other people and businesses, they like to talk, and they don’t, it might slip out...and that’s what you don’t want to be labeled...then I might be shunned.

One participant’s solution for not trusting the privacy at the local pharmacy was to order medications from a company in Winnipeg who sends them in the mail.

Some participants avoided using health or HIV related services in their communities because they knew the people directly involved in providing that service. P17, a young adult woman, described her mistrust being such that if HIV services were available in her community, she would still travel to Winnipeg to maintain her privacy:

To be honest, in [home community], I don’t feel comfortable. If there was [HIV specific service] open, I don’t feel comfortable going, because in [home community], they’re small town mentality and they do a lot of gossip, and I’ve seen it...I’ve seen a lot of people...they’ll be, ‘Oh my God, did you see so and so? She went to this...certain department,’ and ‘I wonder what she has?’ and crap like that.

P08, an older adult man, talked about what he saw as a result of people not trusting in the confidentiality of services offered in his community:

And I know some people feel safer by leaving the community and going to cities which creates additional problem for themselves...they're much more vulnerable, right. But they come [to Winnipeg] to try and get assistance because they don't trust the system at the local level.

Many participants chose to keep silent about their HIV status in their home communities, and prefer accessing services in Winnipeg despite the distance. P08 described why he advised other people living with HIV to be careful about disclosure of their HIV status in rural communities:

I caution them not to [disclose HIV status], because the communities aren't ready for it. I tell them no...If you want to deal with it in your own family, that's fine. Deal with it in there, but be careful about the environment and stuff like that... There's real, there's a real risk to them. Not only internally, but around neighbouring communities as well, there's a real risk to them...They can actually be forced into, into being even more isolated if they [disclose HIV positive status].

A couple of older adult participants described disclosing HIV status to health workers in their community with neutral or positive outcomes. One participant shared that although reluctant, they disclosed their HIV status to a health worker at a flu clinic where they knew some of the workers personally, and felt their privacy was respected. Another participant described not widely broadcasting their HIV status, but felt supported by family and local health workers to whom they had disclosed for health care purposes.

Unique prioritized needs. The prioritized needs described so far are those common needs identified by three or more participants from the study sample. Eight participants identified one unique need that they prioritized at the end of their semi-structured interview, which are listed and briefly described here.

Specific HIV health provider services in small urban centres. A couple of participants prioritized a need for having primary care physicians and allied health workers who specialize in HIV treatment closer by, and suggested having a least one HIV specialized team in the small urban centres throughout the province.

Knowledgeable health care provider that can be trusted. One participant prioritized the need for having at least one health care provider who is knowledgeable about living with HIV. Other desirable characteristics included a non-judgmental approach, and accepting attitude that encourages the person receiving care to be open and honest about their health.

HIV specific health services available on evenings or weekends. One participant identified an unmet need of having appointment time options during evenings or weekends, so as to accommodate work or school hours with limited flexibility or leave time.

Build trust in the privacy and skill of local services. A couple participants prioritized an unmet need of addressing the barrier of lack of trust in local health-related services. Some strategies identified included educating workers about HIV and confidentiality, applying strategies to communicate and ensure privacy to the service recipient, and the importance of building community partnerships so health workers understand community dynamics and can adjust their approach to addressing HIV accordingly.

Supports to attain independent living goals. One participant identified an unmet need related to independent living goals. Some examples of goals included: gaining independence with transportation; living independently; and returning to work.

Internet access and related skills. One participant specifically prioritized the unmet need of having Internet access, and the related equipment and skills to use the Internet at home for HIV health information and peer communication.

Summary of prioritized needs. The qualitative findings described needs identified and prioritized by participants, and included a description of the needs in context of living with HIV outside of Winnipeg in Manitoba. The qualitative findings also included participants' perspectives of resources, barriers and possible solutions to meeting identified needs. Four key themes encompassed identified needs: Access to self-management resources, information and services; access to peer support; education to reduce HIV stigma related experiences; and access to transportation. Access to self-management resources, information and services reflected needs that were essential for life (i.e., a safe place to live; consistent access to HIV medications), as well as needs that were related to being productive and thriving while living with HIV (i.e., access to a Manitoba specific comprehensive resource; self-management supports for healthy living). Access to peer support was a common unmet need that was identified as needed not only at diagnosis, but also throughout one's lifespan while living with HIV. Stigma was a common experience that led participants to identify the need for public and health care and social services worker education. The need for access to transportation revealed predictable barriers related to living in low-density areas, but also revealed systemic barriers from participant perspectives, like certain HIV related treatments not being available in rural areas. Many participants expressed a shared common barrier, related to a lack of trust in locally provided services that involve

disclosing their HIV status, which is described and related to prioritized needs. Finally, some participants prioritized unmet needs that were unique within the sample, such as supports for independent living goals, and Internet access.

The descriptive qualitative findings provide an understanding of needs in context of living with HIV in rural Manitoba at a distance from city centric HIV services. The next section combines the qualitative and quantitative findings to further understand patterns of qualitative needs related to participants' quantitative characteristics.

Mixed Methods Results

To identify patterns of prioritized needs, a joint display analysis was used to show the participant quantitative characteristics associated with each qualitatively identified need. The nine qualitative prioritized needs form the joint display column headings. Qualitative needs were organized into three categories, and one joint display table was created per category, based on participants' description of the need: Table 9, essential needs; Table 10, unmet needs; and Table 11, unmet needs related to stigma. The needs in Table 9 were identified by participants as essential for living with HIV in Manitoba, outside of Winnipeg, and were either unmet or met depending on the participant and timeline. These essential needs were: consistent access to HIV medications; a safe place to live; transportation; and family or surrogate support. Other identified needs were uniformly unmet for participants. These unmet needs were: access to peer support; access to a comprehensive Manitoba specific information resource for living with HIV; and access to self-management supports for healthy living, to work on goals related to healthy eating, weight loss, or exercise (Table 10). Finally, the last two unmet needs related to stigma (Table 11): public education to reduce stigma, and education of health and social services workers to reduce stigma. Some participants prioritized a need that included multiple themes; for example,

prioritizing the need for education of others about HIV, and describing the need to educate both the public and health care workers. In such cases, both needs were counted. In the given example, one count was assigned to the need for public education and one count was assigned to the need for education of health and social services workers. Six participants prioritized a need that fit into two or more subtheme categories such that participants prioritized a total of 60 needs. The eight prioritized needs identified as unique (i.e., chosen by less than three participants), are not included in the joint display tables so as to protect participant identity. Therefore, the joint display tables, Tables 9, 10 and 11, include a total of 52 prioritized needs that fall into the nine subthemes described in the qualitative findings in the previous section.

The joint display row headings display categories of quantitative data and include: socio-demographic characteristics, health characteristics, and PAM-13 data. In general, variable responses were dichotomized and presented as one of two categories, showing how many participants in the sample fit the named category. Exceptions are: years living with HIV and PAM-13 score, where means and standard deviations were calculated; and age category, which is displayed showing all three age categories. Of note, when dichotomizing income, it was chosen to display the number of participants reporting annual income less than \$40,000. Although measures of poverty are complex, the Canadian Centre for Policy Alternatives Manitoba Office (2011) estimated that families of at least two people with annual income of less than \$40,000 are living in poverty or near the poverty line.

The joint display table cells therefore reflect the characteristics of those participants who prioritized each qualitative theme as one of their most important needs for living with HIV outside of Winnipeg in Manitoba. The joint display results are organized in tables and discussed in the following mixed findings.

Essential needs for living with HIV. Table 9 displays participant characteristics of those who prioritized four themes of essential needs for living with HIV outside of Winnipeg in Manitoba: consistent access to HIV medications; a safe place to live; transportation; and family or surrogate support. Participants who prioritized consistent access to HIV medications were a mix of people who had subsidized medications and those who did not, and only half (3 out of 6) reported income less than \$40,000 a year. Participants who prioritized the essential need of a safe place to live, all reported income of less than \$40,000 a year, were mostly unmarried (5 out of 6), and were mostly rural versus small urban area residents (5 out of 6). Participants who identified transportation as an unmet need were younger on average, mostly women (4 out of 5), mostly rural residents (4 out of 5), reported low income of less than \$40,000 a year (4 out of 5), and were all unmarried. Participants who prioritized family or surrogate support all identified as having substantial family support and spoke about how hard it would be for someone without family support living outside of Winnipeg. Participants with family support were mostly men (4 out of 5), mostly educated with at least a high school diploma (4 out of 5), mostly rural residents (4 out of 5), and were mostly recruited from the hospital recruitment site (4 out of 5).

Table 9. Characteristics of Participants Who Prioritized Needs Identified as Essential When Living With HIV at a Distance From Specialized Services in Manitoba

Characteristics	Consistent access to HIV medications <i>n</i> = 6	Safe place to live <i>n</i> = 6	Transportation <i>n</i> = 5	Family or surrogate support <i>n</i> = 5
Socio-demographic characteristics				
Age category, YA/A/OA ^a	1/1/4	0/4/2	1/4/0	0/3/2
Women, <i>n</i> (%)	2 (33)	2 (33)	4 (80)	1 (20)
Education less than high school, <i>n</i> (%)	2 (33)	3 (50)	1 (20)	1 (20)
Income less than \$40,000, <i>n</i> (%)	3 (50)	6 (100)	4 (80)	3 (60)
Married or common-law, <i>n</i> (%)	3 (50)	1 (17)	0 (0)	2 (40)
Rural vs. small urban residents, <i>n</i> (%)	3 (50)	5 (83)	4 (80)	4 (80)
Recruited from site A ^b , <i>n</i> (%)	4 (67)	3 (50)	2 (40)	4 (80)
Telephone access, <i>n</i> (%)	5 (83)	3 (50)	3 (60)	5 (100)
Internet access, <i>n</i> (%)	5 (83)	4 (67)	5 (100)	5 (100)
Health characteristics				
Years living with HIV, mean (<i>SD</i>)	14 (3.8)	15 (3.6)	9 (8.1)	11 (6.1)
Fair or poor health, <i>n</i> (%)	2 (33)	2 (33)	1 (20)	2 (40)
Somewhat or not controlled HIV, <i>n</i> (%)	1 (17)	2 (33)	2 (40)	1 (20)
Patient Activation Measure® (PAM-13®)				
PAM-13 Score, mean (<i>SD</i>)	63.8 (6.5)	62.6 (7.4)	67.3 (10.1)	72.2 (8.3)
PAM-13 Level 4, <i>n</i> (%)	1 (17)	1 (17)	2 (40)	2 (40)

Note. Due to rounding, some totals may not correspond with the sum of separate figures.

^aYA = Young adult, *n*; A = Adult, *n*; OA = Older adult, *n*

^bColumn count of participants recruited from an internal medicine clinic at a large tertiary care hospital in Winnipeg; remaining participants were recruited from a Winnipeg based primary care centre specializing in sexually transmitted infections.

Unmet needs. Table 10 displays participant characteristics of those who prioritized the unmet needs of: peer support; a comprehensive information resource about living with HIV in Manitoba; and supports for self-managing healthy living. The majority ($n = 10$, 59%) of all participants prioritized peer support as an unmet need. Most of these participants had access to telephone or Internet for personal use (8 out of 10). Participants who prioritized the need for a comprehensive resource guide were all men with self-reported well-controlled HIV, but none scored the highest level of four on the PAM-13. Most of these men had telephone access (3 out of 4), but only half (2 out of 4) had Internet access. Participants who prioritized the need for self-management supports were all men with self-reported good or better health, all rural residents versus small urban area residents recruited from the hospital site, and mostly scored below level four on the PAM-13 (3 out of 4). Most of these participants (3 out of 4) also reported other non-HIV infection related health conditions, such as diabetes or hypertension, and had telephone access. However, only half (2 out of 4) had Internet access.

Table 10. Characteristics of Participants Who Prioritized Needs Identified as Unmet When Living With HIV at a Distance From Specialized Services in Manitoba

Characteristics	Peer support <i>n</i> = 10	Comprehensive resource <i>n</i> = 4	Self-management supports for healthy living <i>n</i> = 4
Socio-demographic characteristics			
Age category, YA/A/OA ^a	2/5/3	0/1/3	0/2/2
Women, <i>n</i> (%)	6 (60)	0 (0)	0 (0)
Education less than high school, <i>n</i> (%)	5 (50)	2 (50)	1 (25)
Income less than \$40,000, <i>n</i> (%)	7 (70)	3 (75)	2 (50)
Married or common-law, <i>n</i> (%)	3 (30)	1 (25)	1 (25)
Rural vs. small urban area residents, <i>n</i> (%)	5 (50)	3 (75)	4 (100)
Recruited from site A ^b , <i>n</i> (%)	5 (50)	3 (75)	4 (100)
Telephone access, <i>n</i> (%)	8 (80)	3 (75)	2 (50)
Internet access, <i>n</i> (%)	8 (80)	2 (50)	2 (50)
Health characteristics			
Years living with HIV, mean (<i>SD</i>)	13 (7.1)	13 (1.2)	9 (4.8)
Fair or poor health, <i>n</i> (%)	1 (10)	1 (25)	0 (0)
Somewhat or not controlled HIV, <i>n</i> (%)	4 (40)	0 (0)	1 (25)
Patient Activation Measure® (PAM-13®)			
PAM-13 Score, mean (<i>SD</i>)	63.9 (6.9)	61.8 (6.1)	67.8 (11.5)
PAM-13 Level 4, <i>n</i> (%)	2 (20)	0 (0)	1 (25)

Note. Due to rounding, some totals may not correspond with the sum of separate figures.

^aYA = Young adult, *n*; A = Adult, *n*; OA = Older adult, *n*

^bColumn count of participants recruited from an internal medicine clinic at a large tertiary care hospital in Winnipeg; remaining participants were recruited from a Winnipeg based primary care centre specializing in sexually transmitted infections.

Unmet needs related to HIV stigma. Table 11 displays participant characteristics of those who prioritized themes of unmet needs related to experiences of stigma while living with HIV outside of Winnipeg in Manitoba. More than half of these participants were rural residents versus those living in small urban areas. Eight participants prioritized educating the public living in rural areas to reduce stigma; these participants' mostly self-reported good health or better (7 out of 8). Finally, the four participants who prioritized educating health and social services workers about HIV were all unmarried and all self-reported good or better health, and most of them (3 out of 4) were rural residents.

Table 11. Characteristics of Participants Who Prioritized Needs Identified as Unmet and Related to Stigma When Living With HIV at a Distance From Specialized Services in Manitoba

Characteristics	Educate people living in rural areas about HIV to reduce stigma	Educate health and social services workers about HIV to reduce stigma
	n = 8	n = 4
Socio-demographic characteristics		
Age category, YA/A/OA ^a	1/3/4	0/2/2
Women, n (%)	2 (25)	2 (50)
Education less than high school, n (%)	1 (13)	2 (50)
Income less than \$40,000, n (%)	3 (38)	3 (75)
Married or common-law, n (%)	5 (63)	0 (0)
Rural vs. small urban area residents, n (%)	5 (63)	3 (75)
Recruited from site A ^b , n (%)	7 (88)	2 (50)
Telephone access, n (%)	6 (75)	2 (50)
Internet access, n (%)	7 (88)	3 (75)
Health characteristics		
Years living with HIV, mean (SD)	13 (7.3)	12 (4.8)
Fair or poor health, n (%)	1 (13)	0 (0)
Somewhat or not controlled HIV, n (%)	2 (25)	3 (75)
Patient Activation Measure® (PAM-13®)		
PAM-13 Score, mean (SD)	68.7 (9.2)	67.2 (11.8)
PAM-13 Level 4, n (%)	3 (38)	1 (25)

Note. Due to rounding, some totals may not correspond with the sum of separate figures.

^aYA = Young adult, n; A = Adult, n; OA = Older adult, n

^bColumn count of participants recruited from an internal medicine clinic at a large tertiary care hospital in Winnipeg; remaining participants were recruited from a Winnipeg based primary care centre specializing in sexually transmitted infections.

Chapter 5: Discussion

This study provided a detailed description of the prioritized needs of 17 adult Manitobans living with HIV at a distance from specialized services located in Winnipeg. Understanding common needs and patterns of participant characteristics served as a starting point for identifying high impact goals for the development of sustainable future interventions in collaboration with key stakeholders. Combining mixed methods, and including a process of having each participant prioritize needs that were most important to them, resulted in a participant driven catalogue of needs in this context.

Research Objectives: What was Learned

The following section revisits quantitative, qualitative and mixed method research objectives with discussion of what was achieved.

Quantitative description of participant characteristics. Descriptive statistics from quantitative data show that the study sample was varied and had representation from key risk groups. Women, people reporting heterosexual orientation, people reporting a history of intravenous drug use, and people who self-identified as Indigenous were proportionally over represented in the albeit small study sample when compared to the profile of people entering care in the Manitoba HIV program in 2016 (Manitoba HIV Program, 2017). It is important to note that the Manitoba HIV program annual reports describe people new to care each year, and not a complete profile of all people living with HIV in Manitoba. Additionally, the qualitatively determined sample size was not intended to generalize quantitative results. A strength of this study was the purposeful sampling strategy that facilitated hearing perspectives from a diverse sample of people living in rural areas, who are not always captured in HIV research (O'Brien, Hanna, et al., 2014; O'Brien, Wilkins, Zack, & Solomon, 2010; Rusch et al., 2004).

Qualitative description and interpretation of needs in context. Despite the specific context of living in non-metropolitan areas of Manitoba, the needs participants' prioritized in this study are similar to those found in previous research. A systematic review focusing on barriers to care faced by people living with HIV in non-metropolitan areas of the United States found the most commonly reported barriers to care were related to transportation, stigma, concerns about confidentiality and lack of financial resources, such as paying for medications (Pellowski, 2013). Qualitative Canadian studies also echo similar barriers identified by this study's participants. McCall et al. (2009) reported experiences of Indigenous women living with HIV in British Columbia who experienced difficulty accessing skilled HIV care in non-urban settings, challenges to accessing transportation, fear of disclosing HIV status in home communities due to stigma, and challenges finding safe housing. Groft and Robinson Vollman's (2007) qualitative study of people living with HIV in rural Alberta also described similar issues, such as a need for family support, a healthy place to live, the problem of HIV stigma, and the resulting need for educating people in rural areas about HIV. A lack of trust in confidentiality and skill of local health workers was also noted, leading to challenges related to transportation in order to access specialists (Groft & Robinson Vollman, 2007). Finally, a lack of social support was identified as a barrier to care by Pellowski et al. (2013), aligning with participants of this study identifying the need for access to peer support from rural Manitoba.

Although the common needs found in this study echoed those of previous studies of people living with HIV in rural North America, unique findings arose from seeking out disconfirming evidence within participant narratives, that reinforces the need to extend services and supports to people living with HIV in rural areas. Specifically, some participants felt their

quality of life was improved by living in a rural area, despite the challenges of managing their HIV at a distance from services.

Also unique to this needs assessment was the integration of using mixed methods to assess participants' access and use of, and attitudes towards telephone and Internet for personal use. Although specific programs that use ICTs are described in the literature for addressing HIV related health issues at a distance (Giliauskas et al., 2015), this study sought to understand participant attitudes towards integrating personal telephone and Internet access as a tool to improve access to services in general.

The impact of HIV related stigma on needs. HIV related stigma and discrimination is defined as: "A 'process of devaluation' of people either living with or associated with HIV and AIDS...Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status" (UNAIDS, 2007, p. 9). Participants in this study described how HIV stigma impacts prioritized needs; family support, a safe place to live, access to information, transportation, and the need for education of the public and health workers all related to experiences of stigma. For example, a lack of knowledge about HIV may lead to fear among family members, leading to a lack of support and a need for somewhere else to live. Experiencing stigma is associated with poor outcomes on both physical and mental health (von Hippel, Brener, & Horwitz, 2018). HIV has been stigmatized from the beginning of its awareness in North American, due to its early association with men who have sex with men, people who inject drugs, and death (Gonzalez et al., 2009). Participant narratives in this study suggested that multiple parts of their identity, such as gender, ethnicity, sexual orientation, and health condition often compounded health care barriers that resulted in unmet needs. These barriers affected the person at a personal, family, community, and institutional systems level. The concept of

intersectionality is credited to Crenshaw (1989), a feminist law theorist, and fits with participant experiences. Crenshaw (1989) argued that in a case of exclusion experienced by Black women in a work place, that the “intersectional experience is greater than the sum of racism and sexism” (p. 140), and must be understood to develop useful policy to counteract marginalization.

Intersectionality has appeared in health research that focuses on eliminating health disparity associated with the social determinants of health (Public Health Agency of Canada, 2013; Rapid Response Service, 2013b). Bowleg (2012) defines intersectionality in the context of public health as:

A theoretical framework for understanding how multiple social identities such as race, gender, sexual orientation, SES [socio-economic status], and disability intersect at the micro level of individual experience to reflect interlocking systems of privilege and oppression (i.e., racism, sexism, heterosexism, classism) at the macro social-structural level. (p. 1267)

Rural living, when paired with having HIV, has been found to result in health disparity (Ohl et al., 2013; Trepka et al., 2014). Although using a social ecology framework as opposed to intersectionality per se, Woodgate et al. (2017) found that stigma intersected with determinants of health, including living in small and rural communities, resulting in barriers to health care and support for Indigenous people living with HIV in Manitoba. Given the evidence from previous research, and results from this study, it may be argued that people living with HIV in some rural contexts experience intersectionality, and that application of an intersectionality framework is needed to address the related macro level social inequities (Bowleg, 2012).

A need for peer support access outside of Winnipeg. The need for peer support was the most frequently prioritized need among study participants ($n = 10, 59\%$). Peer support in a health

care context is defined as an arranged service provided by someone with lived experience of the same specific condition or characteristic as the person receiving the service (Dennis, 2003).

Models of peer support range from one-on-one to group, professionally led or peer led, and in person, telephone or Internet based (Canadian Agency for Drugs and Technologies in Health, 2013). Although evidence reviews of comparative clinical effectiveness are mixed and limited, there is evidence that peer support interventions improved HIV related knowledge, perceived experience, aspects of cognition, and risk behaviour for people living with HIV (Canadian Agency for Drugs and Technologies in Health, 2013). Although the evidence is limited for HIV specific outcomes, peer support for people living with long-term and mental health issues has been found to improve experience and emotions, behaviour and health outcomes, and service use and costs (National Voices, 2015). Webel et al. (2013) did find that women living with HIV who felt they had access to social resources and support, were more likely to have positive self-management outcomes, regardless of income. Peer support has also been studied as a way to improve HIV medication adherence, however subjective outcomes such as patient satisfaction have been more conclusive than objective outcomes like reduced viral load (Canadian Agency for Drugs and Technologies in Health, 2013). However, a program evaluation report of a trained peer navigator program for people living with HIV in Vancouver noted a 39% increase in the total number of clients with suppressed viral load after one year of operating the program (Positive Living Society of British Columbia, 2012).

Besides providing needed access to peer support, the development and implementation of a peer support network is an opportunity for the greater involvement of people living with HIV (GIPA; McClelland & De Pauw, 2010). An Ontario based study exploring the level of involvement of people living with HIV in community based research found that HIV service

organizations that included service to rural communities reported lower levels of involvement compared to those serving urban communities (Travers et al., 2008). Travers et al. (2008) noted barriers to engagement of people living with HIV in community based research; it stands to reason that the same additional barriers to care that people living with HIV in rural areas face also impact their opportunities to participate in research. Conscientiously designed community based research to develop peer support access could provide capacity building, training, skills development, remuneration, and dedicated resources to people living with HIV (McClelland & De Pauw, 2010).

The impact of a lack of trust in local services. The majority of participants (71%) expressed a lack of trust in local health services. The primary concern was related to not trusting their privacy would be maintained in accessing local health services, either by health workers directly or indirectly, or inadvertently in public spaces, such as at a local pharmacy or health clinic waiting room. Secondly, a lack of trust was related to participants' perceptions of rural health providers having limited knowledge and skills about HIV. Provider discrimination and stigma, confidentiality concerns, and lack of skilled HIV care are commonly identified barriers experienced by people living with HIV in rural areas (Pellowski, 2013; Rapid Response Service, 2013a).

Participants described privacy as a difficult thing to achieve in a small community. Many chose to not risk a lack of control over their HIV status disclosure by using health services outside of their home community, leading to the burden of expending additional resources and a need for transportation. Woodgate et al. (2017) heard similar concerns from Indigenous people living with HIV on First Nations reserves. The risk of knowing people involved in providing care was a common issue for participants in this study and in Varcoe and Dick's (2008) study of

Indigenous women's experiences in rural British Columbia. Likewise participants were concerned that others would overhear health information in clinic waiting areas or pharmacies. Several participants noted how the physical environment contributed to their lack of trust in privacy. Evidence supports the impact of the physical environment in health care settings on confidentiality and speech privacy (Anjali & Ulrich, 2007). Studies in emergency departments have shown that perceived lack of privacy may lead to some patients withholding health information (Barlas, Sama, Ward, & Lesser, 2001; Nayeri & Aghajani, 2010). Another issue related to the built environment and privacy, was that many participants noted not wanting to attend locations that were identifiable as being an HIV service. This finding was also reported by Woodgate et al. (2017) and Huff et al. (2015).

Participants in this study reported experiences consistent with other research that health care workers in rural areas are often not knowledgeable enough about HIV to provide comprehensive answers to their health questions (Ohl et al., 2013; Veinot et al., 2010). Participants indicated a preference for specialist care for HIV. Previous research supports that care from physicians with specialist or extra training in HIV results in the best care outcomes for people living with HIV (Snyder, Kaempfer, & Ries, 1996; L. Solomon, Flynn, & Lavetsky, 2005). Some participants identified a need for specialists to be available in their home communities, or at least in closer small urban communities. Urban outreach, shared care, and enhanced clinic models of rural HIV care are options that can provide people living with HIV in rural areas access to HIV specialist care (McKinney, 2002). Participants in this study described being happy with their specialist care, but some noted the barrier of a lack of specialized HIV services closer to home, of which existing outreach models may provide feasible options;

however ongoing funding for current programs can be a challenge (Nine Circles Community Health Centre, 2017).

Telephone and Internet access in context of prioritized needs. The use of various ICTs has long been considered as a way to reduce known barriers to care, such as reducing the need for transportation, addressing concerns about privacy and stigma, and a lack of access to specialized care (Aoki et al., 2003; Laurent, 2002; Rapid Response Service, 2013a). ICTs have been used to: access HIV specialists at a distance; connect with peer support; access specialized therapies related to managing HIV and related health issues; and for learning about HIV (Giliauskas et al., 2015; Horvath et al., 2013; Rapid Response Service, 2013a; Zhang & Li, 2017). However, other literature has found a rural-urban divide with regards to access and use of the Internet, indicating that people living in rural areas may be less likely than urban counterparts to be using the Internet (Haight et al., 2014; Noce & McKeown, 2008; Veinot et al., 2010). Specifically in Manitoba, limited infrastructure in some areas of the province has resulted in poor, inconsistent or non-existent cellular phone and Internet service (Canadian Internet Registration Authority, 2016; Melvin et al., 2015). Due to these known barriers, this study sought to understand participants' experiences, attitudes, resources and barriers related to access and use of the Internet for personal use.

Findings related to the UTAUT2 questions (Venkatesh et al., 2012) suggest some positive indications that participants with personal Internet access have a behavioural intention to continue using the Internet for personal use. Overall, participants indicated their personal Internet was easy to use and that they perceived having sufficient facilitating conditions to support use from where they lived. Facilitating conditions were found to be especially influential in predicting intention and use for older women who were less experienced with a new technology

(Venkatesh et al., 2012). The majority of participants using the Internet also found it beneficial in their daily life, despite more mixed responses regarding price value.

Although most participants had access to telephone and/or Internet, a few did not.

Participants without a telephone or without Internet access reported the main barriers were cost and a lack of Internet knowledge and skills. Participants without Internet access also had lower PAM-13 scores, suggesting lower self-reported efficacy, knowledge and skills for health management (Hibbard et al., 2004), and the potential for relatively worse clinical outcomes (Marshall et al., 2013). The United Nations et al. (2011) recognized access to Internet as necessary for supporting rights such as education and health care, and “recognised the duty of States to promote universal access to Internet” (Centre for Law and Democracy, 2012, p. 8).

Although the Canadian Radio-television and Telecommunications Commission (CRTC) has committed to improving access to quality Internet service such that 90% of Canadian homes will have access to fixed broadband Internet by 2021 (CRTC & Government of Canada, 2016b), they do not intervene in the cost of service delivered by provider companies (CRTC & Government of Canada, 2016a). Currently there is no subsidy for Internet costs for people with low income in Manitoba. Although people without Internet in urban centres may access the Internet for free in public places, people in rural areas have less access to such areas. A preliminary pilot of a pending randomized controlled trial found that group based training sessions involving learning how to use the Internet and a web-based personal health record improved patient activation and health literacy, particularly for people living with HIV with lower activation levels (Fiscella et al., 2015). Greene et al. (2015) found in their longitudinal observational study that people with higher PAM scores were less likely to have hospital utilization or emergency department visits, and that health care costs were lower for those with activation levels of 3 or 4 versus levels 1 and

2. Hibbard et al. (2007) found that increases in level of activation measured by the PAM were associated with improved self-management behaviors, such as following a low fat diet, exercising regularly, and managing stress.

For the majority of participants with Internet access ($n = 14$, 82%), most indicated positive intention to continue using the Internet for personal use. A qualitative case study from Northwestern Ontario reported that 47% of 59 participants had categorically positive responses when asked about their thoughts on using videoconferencing and other ICTs for accessing a mental health service from a distance (Gibson et al., 2011). Although barriers to delivering services using ICTs still exist, for those participants who have the means and are willing, using ICTs such as Internet and telephone may be an affordable way to provide services to people living in rural areas, and allow redistribution of funds to provide more in-person support to those people with more significant barriers to care. Participants from this study proposed ways that telephone and Internet could help with access to information, resources and supports from where they lived.

Access to peer support. Participants envisioned accessing a peer support program through a toll free telephone number that they could call, mobile phone text messaging, or an online application that only permitted access to people living with HIV. Participants described wanting one-to-one and group peer support. A review of 524 outcome studies on peer support found the following models most effective: (1) trained peers leading face-to-face, weekly groups for a set number of weeks; (2) trained peers providing one-to-one support, face-to-face or by telephone; and (3) online discussion forums for improving knowledge about HIV and decreasing anxiety (National Voices, 2015). Some participants described wanting to talk to a peer that was similar to them in gender, age and other characteristics. Evidence suggests that customizing interventions

to key populations based on characteristics such as gender, age, and ethnicity may be more effective (Rapid Response Service, 2014), and fits with using an intersectionality perspective to tailor interventions for people experiencing multiple social identities and systemic oppression (Bowleg, 2012; Rapid Response Service, 2013b). Gonzalez et al. (2009) found that women living with HIV in rural areas experienced more concerns about disclosure compared to urban counterparts, and suggest this may increase their risk for social isolation and psychological challenges. Varcoe and Dick (2008) relay the risk of violence and HIV for rural living Indigenous women in a “neo-colonial Canadian context” that results in social and psychological isolation from personal and systemic supports. The threat of violence supports the need for secure and confidential Internet or telephone delivered supports so that women may connect safely with others outside of their community despite often limited means (Gonzalez et al., 2009).

Comprehensive information resource about living with HIV in Manitoba. Participants identified an unmet need for a comprehensive resource containing provincial specific information about living with HIV. Participants indicated needing a resource that comes from a trustworthy source. Qualitative findings suggested that participants’ needs changed over time, either with changes in relationship status, ageing, or through the process of coming to terms with their HIV diagnosis. For some participants who experienced significant illness and hospitalization when first diagnosed, it may take time after initial recovery to identify what their needs are. This suggests that having access to an up to date resource over time, not just at diagnosis, is needed. Access to a comprehensive resource from the onset of diagnosis would give people control of when they choose to learn more about living with HIV. For participants in rural areas, having access to a comprehensive resource may be particularly important, as they may

have limited to no access to in-person, HIV specific information and services in their home community (Veinot & Harris, 2011). Some participants pictured an online resource. One benefit of an online resource includes being able to update the resource with minimal costs and time compared to print resources. Another benefit to an online resource is that it allows users additional privacy compared to having a paper copy resource in their living space. Finally, an online resource would also allow the use of multi-media to communicate content in ways that may be more accessible for some users. For example, videos could be used to relay content in spoken word, or different languages that are prevalent in the province. Developing and testing the content of a comprehensive provincial specific resource could provide another opportunity for the greater involvement of people living with HIV (McClelland & De Pauw, 2010).

Self-management tools and supports. Participants identified a variety of needs related to self-management of health behaviours such as healthy eating, safe weight loss, time management and exercise in the context of living well with HIV. A scoping review of self-management programs for people living with HIV concluded they helped make positive changes in health behaviours (Bernardin et al., 2013). Bernardin et al. (2013) also note the importance of tailoring interventions to participant needs, cultural context and experience level. The importance of tailoring content in order to be effective was also found in a systematic review of self-management interventions delivered using website applications or mobile telephones (Zhang & Li, 2017). Other qualitative research has identified the need to provide adequate support and guidance to people living with an episodic health condition who want to integrate health information into their daily life activities (Restall et al., 2017).

In this study, all the participants who prioritized the need for self-management supports were men. Gender differences in terms of the content needed in self-management programs for

people living with HIV has been noted (Bernardin et al., 2013). Women living with HIV have been noted to experience disparity in terms of barriers and health outcomes (McCall et al., 2009; Webel et al., 2013), which may have led women in this study to prioritize other needs like peer support and transportation. Risk of violence may also be a factor in the lives of rural women who are living with or at risk for having HIV (Varcoe & Dick, 2008), and concerns about privacy and disclosure (Gonzalez et al., 2009) may supersede concerns about diet and exercise. A socially supportive context and having a role as an employee have both been found to result in improved self-management behaviours for women living with HIV, such as engagement in health care, healthy eating and exercise (Webel et al., 2013). This suggests that interventions to address peer support needs and structural barriers to employment faced by women living with HIV, may improve self-management behaviour and consequently health outcomes. In line with an intersectionality perspective, other research supports the need to address systemic factors that prevent self-management goals, such as historical discrimination and safety (Bowleg, 2012; Webel et al., 2013). The importance of developing interventions that are culturally tailored and guided by the community of interest, including people experiencing intersectionality, is a recurrent theme and supports the use of a community based research approach (Bowleg, 2012; Rapid Response Service, 2013b; Varcoe & Dick, 2008; Woodgate et al., 2017).

Rehabilitation professionals, such as occupational therapists have been identified as well suited for working with people living with HIV on self-identified goals requiring tailored, context specific interventions (Bernardin et al., 2013). Additionally, access to integrated rehabilitation services, and living well with HIV were identified as research priorities by a group of diverse stakeholders, half of which were people living with HIV (Restall et al., 2016). Finally, using a client-centred approach, occupational therapy could determine on a case-by-case basis

appropriate technologies to use with clients living at a distance to support their self-management goals.

The need for consistent access to HIV medications. Consistent access to HIV medications may be considered a high risk need, given the consequences of interrupted use of HAART. Research has shown that lifetime adherence to a daily, scheduled medication regime is required when taking HAART to reduce viral load (National Collaborating Centre for Infectious Diseases, 2010; Paterson et al., 2000), and reduce the risk of medication resistance (U. S. Department of Health and Human Services & Health Resources and Services Administration, 2014). Adherence to HAART is associated with better health outcomes for people living with HIV and prevention of transmission of HIV to others (U. S. Department of Health and Human Services & Health Resources and Services Administration, 2014). Some participants spoke of not taking HAART for periods of time due to not being able to afford medications. Canadian research estimates that 10% of people with a prescription do not take their medication as prescribed due to cost related barriers (Law, Cheng, Dhalla, Heard, & Morgan, 2012). The rates of cost-related prescription non-adherence are reported as higher for people with income under \$50,000 (Butler, 2017). Although the needs of having consistent access to HIV medications may be a similar problem for people living with HIV in a more urban environment, there may be fewer jobs that offer prescription health benefits in rural versus urban areas. Employer paid drug plans are less likely for people earning less than \$20,000 a year, people working part-time, and for women (Barns & Anderson, 2015). Even with a provincial prescription subsidy program, participants still spoke of not being able to afford program minimums. The study findings indicate there may be a gap between people receiving income assistance, who have their

medications covered, and those who have sufficient income to pay provincial or private health care plan premiums, consistent with reports from Barns and Anderson (2015).

Conceptual alignment of study findings with the EDF

This study sought to identify and understand participant needs that if met, would address barriers to their activity and participation in their daily life. Barriers to activity and participation are analogous to the *dimensions of episodic disability* in the EDF (O'Brien et al., 2008). The needs identified by participants were situated in an overarching context of living with HIV at a distance from specialized services in Manitoba, and were the result of *extrinsic* and *intrinsic* factors relative to participants that would exacerbate disability when not addressed (O'Brien et al., 2008). The needs identified and prioritized in this study related to all four contextual factors in the EDF: social support and stigma (extrinsic factors), and living strategies and personal attributes (intrinsic factors; O'Brien et al., 2008). However, the majority of needs prioritized by participants in this study related to social support factors. The EDF includes *triggers of disability*, defined as events that bring on episodes of disability (O'Brien et al., 2008).

Participants reported examples of triggers through their description of barriers and needs. Figure 9 illustrates how the needs prioritized by participants in this study align with the contextual factors of the EDF, and provides examples of triggers that point to when intervention supports may be needed to reduce disability.

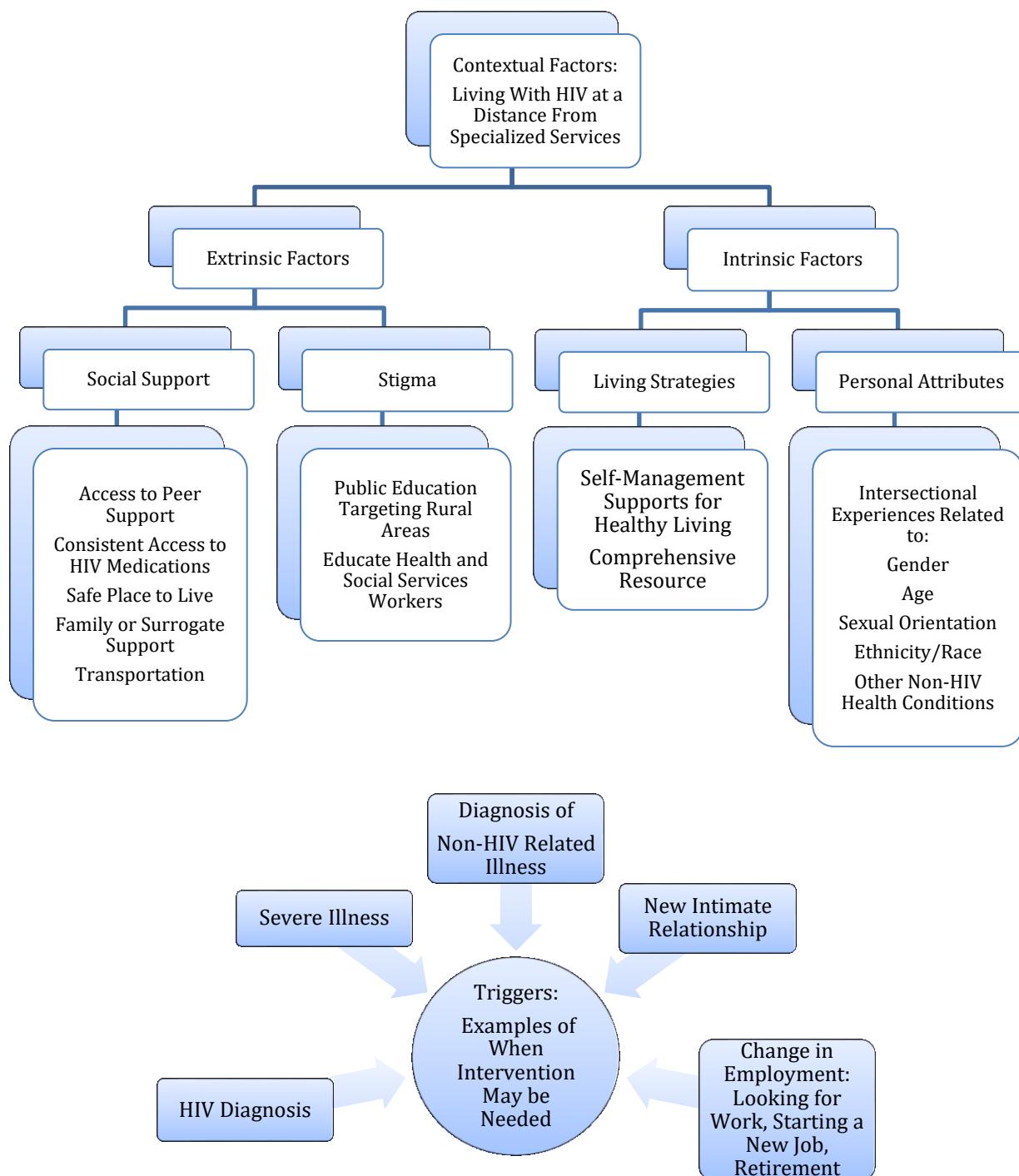


Figure 9: Prioritized Needs of Participants Living With HIV at a Distance From Specialized Services in Manitoba, Applied to the Episodic Disability Framework (EDF). Needs aligned with contextual factors of the EDF. Participants identified examples of triggers of disability, or when intervention may be needed. Adapted from “Exploring disability from the perspective of adults living with HIV/AIDS: Development of a conceptual framework”, by K. K. O’Brien, A. M. Bayoumi, C. Strike, N. L. Young and A. M. Davis, 2008, *Health and Quality of Life Outcomes*, 6:76. Copyright 2008 by O’Brien et al; BioMed Central Ltd., under Creative Commons Attribution License (<http://creativecommons.org/licenses/by/2.0/>).

The EDF was developed from perspectives of a sample of participants that did not include people living in rural areas, or Indigenous people (O'Brien et al., 2008). This study data supports that the contextual factors and trigger components of the EDF are a good fit for understanding the contextual needs and when supports might be needed from the perspectives of people living with HIV in rural areas, including people who self-identified as Indigenous. The contextual needs stemmed from participant descriptions of barriers that also aligned with the EDF dimensions of episodic disability. Findings clearly identified symptoms/impairments, difficulties with day-to-day activities, challenges to social inclusion, and uncertainty that participants experienced, ultimately leading to the prioritized needs. An intended use of the EDF was to identify modifiable contextual factors that can be the focus of developing interventions to address or prevent disability experienced by people living with episodic health conditions such as HIV (O'Brien, Davis, Strike, Young, & Bayoumi, 2009). Although self-management supports for healthy living may be considered a modifiable factor that can be addressed at a person level using rehabilitation approaches (Bernardin et al., 2013), the remaining modifiable factors involving social support and stigma are better addressed at a macro, social systems level (Bowleg, 2012). Authors of the EDF also note the importance of understanding and researching non-modifiable personal attributes that contribute to disability, such as age, gender and co-morbid health conditions (O'Brien et al., 2009). In these ways, the EDF may provide a framework for applying an Intersectionality perspective for rehabilitation as described by Bowleg (2012).

Implications

This study reported the unheard perspectives of people living with HIV at a distance from specialized services in Manitoba, regarding prioritized needs to address disability experienced at

a personal, community, and social systems level. The findings have clinical, research and policy implications.

Clinical implications. Clinicians working with people who are living with HIV in rural areas may use the findings in several ways. For clinicians new to working with this population, the description of participants' needs in context may deepen understanding of the barriers clients may face when living at a distance from services. Being aware of potential triggering events in clients' lives provides a cue for clinicians to reassess needs that may fluctuate with episodic experiences of disability. With understanding, clinicians may be better positioned to assess and address needs within the context of their existing practice that may fluctuate or change throughout the course of their client's lifespan.

Experienced front line clinicians may use these findings to support their advocacy for universal access to HIV medications. Experienced providers in Manitoba are also well suited to contribute to the development of accessible information resources specific to their services that meet information needs identified in this study. Awareness of the varied needs identified by participants in the study may also help clinicians be more aware of existing services and supports that have the potential to be extended to people living in rural areas, regardless of what program site they attend.

Occupational therapy is a potential intervention for addressing self-management goals for people living with chronic health conditions (Bernardin et al., 2013). The Manitoba HIV Program has an occupational therapist based out of their community health centre site; however all of the participants who prioritized needing self-management supports for healthy living received care at the tertiary hospital site. Offering occupational therapy from the tertiary site may improve supports to people living at a distance from Winnipeg. Some participants did indicate a

preference for attending a clinic site that was not identifiable as an HIV specific service, and thus preferred to receive services from the tertiary care site instead of the community primary care site. Improving access to supports and services from a distance may help people living with chronic conditions in rural areas maintain health and reduce overall health care utilization needs (Krentz & Gill, 2015; National Advisory Committee on Rural Health and Human Services, 2011). There is support in the literature for ongoing versus one-time assessment of goals related to evidence that people living with HIV may change the focus of their self-management goals over time (P. Solomon et al., 2018)

Occupational therapy may also address functional performance issues that impact adherence to HAART, and related health outcomes. Cognitive deficits, difficulties with problem solving, low mood or depression, impaired coping, and limited social supports are all potential difficulties for people living with HIV, and particularly for those aging with HIV, that may also impact HAART adherence (Canadian Working Group on HIV and Rehabilitation, 2015; Escota, O'Halloran, Powderly, & Presti, 2018; P. Solomon et al., 2018). Occupational therapists can facilitate tailored interventions based on an individual's specific context. Stress and coping management, problem-solving strategy development, and individual and group therapy approaches may be used to address performance issues in occupational therapy. Additionally, adaptive aids and compensatory solutions can be devised in partnership with the person living with HIV and occupational therapist, with an aim to support functional performance, including HAART adherence (Canadian Working Group on HIV and Rehabilitation, 2015).

Including an assessment of individual client's access, use, and skills related to telephone and Internet use may opportune tailored ways of improving access to services, supports, and HIV information in between in person visits. For example, if a client has personal access to Internet

and is familiar with using videoconferencing applications, follow-up appointment could be scheduled via videoconference when in-person appearances are not necessary. Or, pre-existing interventions that address client identified goals may be offered to clients who have the requisite ICT access.

Regarding improving trust in rural services, and improving connection of people living with HIV in rural areas with primary care providers closer to home: the experienced and trusted clinicians of the Manitoba HIV Program also have the potential to play an important role in identifying, partnering with, and developing the capacity of health providers who are situated within each of the province's health regions, and who are willing to become champions of HIV care. These champions in partnership with clinicians of the Manitoba HIV Program can meet the identified need to address community specific contexts in HIV prevention, treatment and care approaches.

These findings may point to areas of intervention that can be integrated into existing practice to improve a client's progress on the HIV Care Cascade towards viral suppression as a result from retention in care and treatment (Manitoba HIV Program, 2017). All participants in this study were on HAART, and, although participants' viral load was not directly measured, participants who reported their HIV was *well controlled* generally stated they had suppressed viral load at their last appointment. Only 71% of participants reported their HIV was *well controlled*, compared to 83% of all clients entering care in the Manitoba HIV Program having suppressed viral load in 2016 (Manitoba HIV Program, 2017). Client's living at a distance from specialized services may need extra clinical supports to overcome contextual and systemic barriers such as those identified in this study, in order to achieve and maintain suppressed viral load.

Research implications. The study findings have implications for future research. Given the importance of personal characteristics related to identified needs, and the tailoring of effective interventions for people living with HIV and other chronic health conditions (Bernardin et al., 2013; Hibbard et al., 2009; Rapid Response Service, 2013b), population data regarding the characteristics of people living with HIV in different regions of the province would be helpful.

Community based research approaches are ideal for taking action towards meeting unmet needs identified in the findings, promoting the greater involvement of people living with HIV (McClelland & De Pauw, 2010), and are a good fit with applying an intersectionality framework (Rapid Response Service, 2013b). HIV related stigma has been recognized as a significant barrier to preventing, treating and supporting people living with HIV in Manitoba (Nine Circles Community Health Centre, 2018). Combating stigma has been identified as one of three strategic action targets by the Manitoba HIV Collective Impact Network, and several related community based research projects are ongoing (Manitoba HIV Collective Impact Network, 2017).

Given the high priority placed on peer support by participants in this study, and other recent community based research identifying peer support as a need (University of Manitoba & Nine Circles Community Health Centre, 2017), the development of a peer support network in Manitoba is an ideal opportunity for involving people living with HIV in rural Manitoba in community based research. Community based research projects with higher budgets have been found to report higher involvement of community members, supporting the need to remove barriers to participation through securing funding for travel costs, childcare and other costs of participating (Flicker, Savan, Kolenda, & Mildenberger, 2008), which may be more involved for rural participants, and include reimbursement for communicating at a distance.

Several existing peer support programs have components that aim to reach people living with HIV in rural areas, despite being based out of larger centres. The Positive Living Society of British Columbia launched a Peer Navigator program in 2011. Trained peer Navigators have been integrated into interdisciplinary health care clinics in Vancouver, as well as working as Outreach Peer Navigators in the community. The program focuses on services for people newly diagnosed with HIV, or those at risk for not maintaining connection with HIV health care. Program goals include improving connection with treatment and supports for people living with HIV, and therefore reducing transmission of HIV and delaying disease progression. Support activities include emotional support, HIV literacy, supporting behaviour change and encouraging harm-reduction strategies. Besides one-to-one support, peer-to-peer self-management education groups are also offered through the program. Although Vancouver based, the program describes being able to connect face-to-face with rural clients who, like in Manitoba, travel to Vancouver regularly for care at an immunodeficiency clinic, and connect by telephone in between visits (Positive Living Society of British Columbia, 2012).

Another program launched in Regina, Saskatchewan in 2012, called the Peer-to-Peer Program, referenced and received guidance from the Vancouver Peer Navigation program. Tailored telephone, face-to-face and community support is provided to people living with HIV matched with trained peers living with HIV. The need to support people living with HIV in rural Saskatchewan is recognized by the program planning to explore expanding the Peer-to-Peer Program by joining with HIV specialists in rounds to rural areas. Securing long-term funding is noted as a challenge to the project (CATIE, 2014).

An example of another peer support program can be found in London, Ontario. Saint Joseph's Hospital Infectious Diseases Care Program described a peer mentor role that supports

people living with or at risk of HIV infection. The program operates by interested persons calling a local telephone number and leaving a message, to which peer mentors return the call, answer questions, and provide support. Regardless of the model, a key partner in addressing the need for peer support and engagement of people living with HIV in rural Manitoba is the Manitoba HIV Program.

Development of a comprehensive information resource for people living with HIV in Manitoba also presents opportunities to engage people living with HIV from rural areas. The information needs identified in this study may serve as a starting point for content development. Community members could then be engaged to give feedback on content development, and guide format delivery and evaluation.

One study objective included survey and exploration of participants' personal access and use of telephone and Internet. The intent was to understand the barriers and resources related to meeting identified needs of people living with HIV in rural areas of Manitoba with services delivered using ICT. Personal Internet access and use of mobile devices was common among participants and many suggested ways that unmet needs of access to peer support and a comprehensive information resource could be addressed through use of ICTs. The use of commonly available ICTs such as telephone and Internet should be considered in both extending existing services available in Winnipeg to people living with HIV elsewhere in the province, as well as in the development of new services to address identified needs. The UTAUT2 framework for predicting acceptance and use of a newly introduced technology can help guide effective intervention development through further study of and attention to the UTAUT2 factors and demographic characteristics shown to influence voluntary continued use of a new technology application (Venkatesh et al., 2012). For example, interventions may need to build in supports

targeted at older men with experience using a particular technology as evidence shows they may be less likely to make changes in their habits in order to successfully adopt a new application. For younger adult users, the factors of performance expectancy and hedonic motivation were found to be important predictors of behaviour and use of a new health application (Yuan, Ma, Kanthawala, & Peng, 2015).

Application of the EDF in future research may be used to quantify dimensions of disability for people living with HIV (O'Brien, Davis, et al., 2014). Pre and post measures may then be used to evaluate the outcome of future interventions developed to address contextual factors. Applying an intersectionality perspective (Bowleg, 2012) to the EDF may contribute to better describing and quantifying disability that results from the intersection of multiple, specific personal attributes and macro-systems level policies and institutions.

Policy implications. Several prioritized needs require macro-systems level change, such as the high risk need for consistent access to HIV medications. Canada is touted as "...the only country with a universal national public health care plan not to include prescription drug coverage" (Butler, 2017, p. 4). Participants who prioritized consistent access to HIV medications as a need, saw universal access to HIV medications as a solution to meet this need. Advocates for a universal prescription drug plan argue that it would result in better health outcomes for citizens, reduced national total spending on prescription drugs, and benefit businesses by relieving costs of private plans for employees (Butler, 2017; Citizens' Reference Panel on Pharmacare in Canada, 2016). The Manitoba HIV Program (2017) also noted that "Provincially-funded HIV medications would make treatment more accessible, improving health outcomes for individuals and supporting prevention efforts in the community" (p. 1). The Citizens' Reference Panel on Pharmacare in Canada (2016) and Butler (2017) recommend initial actions, follow-up

actions and suggested models for funding a transition to a universal Canadian Pharmacare program.

Although not a policy issue, participant concerns regarding inconsistent handling of blood samples for valid HIV viral load analysis may be worth investigating at an institutional level. The Cadham Provincial Laboratory is responsible for infectious serology and laboratory services in Manitoba (Cadham Provincial Laboratory, 2015).

Evidence is accumulating to justify advocacy for subsidized Internet access for those people who cannot afford it. Future research into the effect that Internet access and skill has on level of activation and health literacy may be worthwhile to determine if there is a cost utility to providing Internet access and training for people with chronic health conditions and insufficient income to afford Internet access. A qualitative study of health literacy among people living with HIV in rural areas also recommended further study of how to strengthen effective Internet skills and configure supports and services to meet health literacy needs (Zukoski et al., 2011).

Finally, architectural design solutions and environmental assessment methods are available for improving patient privacy in a health care context (Anjali & Ulrich, 2007). Given the potential high-risk impacts on health outcomes, such as avoidance of seeking health care, and providing incomplete health information when receiving care, a systemic course of action to apply feasible solutions for retrofitting existing spaces for improved privacy is warranted, particularly in rural areas due to increased privacy concerns noted in the literature. Participant reports suggest community health centres and pharmacies are key environments to target for improved privacy. Changes to the built environment that improve privacy have the potential to improve the quality of care and health outcomes for all patients (Anjali & Ulrich, 2007), including those living with HIV.

Limitations of the Study

Given the objective of understanding the varied needs of people living with HIV in rural Manitoba, there were some limitations related to the final sample characteristics and size. All participants were connected with HIV specialist care and were all on HAART. Therefore, the findings are biased towards participants who, despite living at a distance from services, are connected to specialized care. The needs of people living with HIV who are not connected with specialized care may differ.

A limitation of this study may be the proportional underrepresentation of men who have sex with men and Black people of African or Caribbean descent when compared to provincial data regarding characteristics of those new to HIV care. Participants in the sample did represent both groups. It could be that, although men who have sex with men and Black people accounted for many of those new to care in the Manitoba HIV program in 2016 (25% and 31% respectively; Manitoba HIV Program, 2017), perhaps they are more likely to live in Winnipeg compared to rural or small urban centres, or feel less safe self-identifying in a research context. Participant narratives supported that men who have sex with men experience stigma and fear for their safety related to their sexual orientation in some rural communities. Qualitative accounts of gay men living in rural North America have reported similar experiences (Groft & Robinson Vollman, 2007; Williams et al., 2005). Specific barriers of social hostility and violence towards men who have sex with men living in rural areas are reported in the literature; these barriers are also experienced by women (Rapid Response Service, 2013a).

Although this study aimed to recruit a sample with at least half women, women represented only 42% of the sample. Women who were currently parenting young children at home were particularly difficult to engage in the study. Despite offering flexible times and

formats to participate, only one mother with young children at home completed the study. Mothers living with HIV who are parenting children at home may have additional or different needs that were not identified in this study. There was also an absence of women participants from Northern and Southern Health Regions, which may suggest unidentified needs for women that may be particular to living with HIV in these areas.

Ultimately the time needed to recruit participants living outside of Winnipeg was a limiting factor. Although recruitment strategies were successful in connecting with rural living participants, more time would have been needed to reach a larger sample size that could have targeted inclusion of more men who have sex with men, Black people, and mothers with young children at home. The data collection phase took longer than planned (Appendix B) and ultimately was limited by degree completion requirements. Although the minimum sample size was surpassed, it was too small to compare needs between different health regions.

Regarding quantitative data collection, the choice to collect all questionnaire data by the principal investigator reading and recording responses resulted in the potential for positive response bias. Participants may have answered questions in a way that reflected their perception of socially acceptable answers. Regarding qualitative data, participants provided both current and historical accounts of their experiences that related to their perception of needs. Current contextual factors may or may not result in the same conditions and needs as participant experiences that happened in the further past.

Other limitations relate to understanding access and use of the Internet. Questions from the UTAUT2 model were modified to specifically ask about personal Internet access and use, assuming this condition would be the most accessible for participants. However, as some participants elaborated, regular personal use of the Internet does not mean that a person would

use the Internet to access health care services. Concerns about privacy and security while using the Internet were noted. More specific investigation regarding attitudes and needs related to accessing health care treatments using personal ICTs may be needed and should be considered specifically in the development of an intervention.

Finally, the questionnaire regarding Internet access and use did not collect data about what specific Internet applications people use, e.g., web browsing, email, or social media applications. The implication may be that a participant could be a daily email user, but may not use any other Internet applications and struggle to adopt new or more complicated applications.

Knowledge Translation

Knowledge translation is defined as “a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system” (Canadian Institutes of Health Research & Government of Canada, 2017).

Knowledge translation for this study will focus on dissemination of study findings and exchange of findings with potential key stakeholders identified in Table 12 who may help with converting results of the study to change action aimed at improving activity and participation of people living with HIV in rural Manitoba.

The Canadian Institutes of Health Research (2016) describes dissemination as conveying results to key stakeholders by delivering research information in ways that are appropriate and relevant for each audience. Exchange of knowledge is described as “the interaction between the knowledge user and the researcher, resulting in mutual learning”, with the goal of applying the results to improve existing health systems (Canadian Institutes of Health Research &

Government of Canada, 2016). Table 12 outlines completed and planned knowledge translation activities.

Table 12. Knowledge Translation Plan

Domain (Status)	Potential Audience	Activity
Dissemination and Exchange (In Progress)	Participants	Share preliminary summary reports with participants who consent to receive them. Receive and integrate participant feedback regarding preliminary summary reports.
Dissemination (Pending)	Regional Primary Care Contacts and Manitoba HIV Program	Provide final summary reports to key primary care providers to make available to people living with HIV in a confidential and voluntary manner.
Dissemination and Exchange (Pending)	Manitoba HIV Program, Manitoba Health, Manitoba HIV Collective Impact Network, Assembly of Manitoba Chiefs, First Nations and Inuit Health Branch, and People Living with HIV in Manitoba	Present findings to key stakeholders; organize an interactive meeting to brainstorm and problem solve solutions for change.
Dissemination (Pending)	Academics, Clinicians, Researchers, and Policymakers	Publications and presentation of study results, recommendations, and process.

Conclusions

People living with HIV in rural and small urban areas of Manitoba outside of Winnipeg identified nine commonly shared needs. Needs aligned with the EDF contextual factors and related to need for social support, stigma, and living strategies. Experiences described by participants suggest multiple personal attributes intersect with other contextual factors resulting in barriers such as sexism, ageism and racism. A common barrier shared across varied personal

characteristics was a lack of trust in the safety of disclosing HIV in rural and small urban area communities. A resource for augmenting access to services may be found in using commonly held ICTs such as telephone and Internet, and applying evidence based frameworks such as the UTAUT2 to guide intervention development.

Actions to address identified needs are recommended to occur at clinical, research and policy levels to address complex contextual factors that can reduce or eliminate experiences of disability for people living with HIV in rural areas of Manitoba. Knowledge translation activities involving key stakeholders are required for collaborative, sustainable solutions to meet identified needs and must include people living with HIV from rural areas to be ethical and effective.

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Footnotes

¹See Appendix A for further information and relevant references regarding the Patient Activation Measure® (PAM®).

²See Appendix E for the questionnaire used to gather data related to participant access and use of the telephone and Internet for personal use.

³See Appendix F for the questionnaire used to gather demographics and history data.

⁴See Worthington et al. (2005) and O'Brien et al. (2008) for literature regarding the development of the Episodic Disability Framework.

Appendix A: Patient Activation Measure®

The Patient Activation Measure® (PAM®) is a licensed, commercial measure of self-reported efficacy, knowledge and skills to manage one's health (Hibbard et al., 2004). Higher PAM scores have been associated with better clinical outcomes (Marshall et al., 2013). For the purpose of this study, a one-year research license for graduate study use with up to 250 participants was secured in 2016.

The study used the PAM-13 as a part of data collection. The PAM-13 has been found to be reliable and has been validated (Hibbard et al., 2005). The PAM-13 has been used with rural populations (Hung et al., 2013), in-person and over the telephone (Hibbard et al., 2004), and with people living with HIV (Marshall et al., 2013).

The PAM-13 measure is published and can be reviewed in:

Hibbard, J. H., Mahoney, E. R., Stockard, J., & Tusler, M. (2005). Development and Testing of a Short Form of the Patient Activation Measure, 40(6P1), 1918–1930.

The original development of the PAM is described here:

Hibbard, J. H., Stockard, J., Mahoney, E. R., & Tusler, M. (2004). Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Services Research*, 39(4p1), 1005–1026.

Other related PAM literature:

Greene, J., Hibbard, J. H., Sacks, R., Overton, V., & Parrotta, C. D. (2015). When Patient Activation Levels Change, Health Outcomes And Costs Change, Too. *Health Affairs*, 34(3), 431–437. <http://doi.org/10.1377/hlthaff.2014.0452>

Hibbard, J. H., Greene, J., & Tusler, M. (2009). Improving the outcomes of disease management by tailoring care to the patient's level of activation. *The American Journal of Managed Care*, 15(6), 353–360.

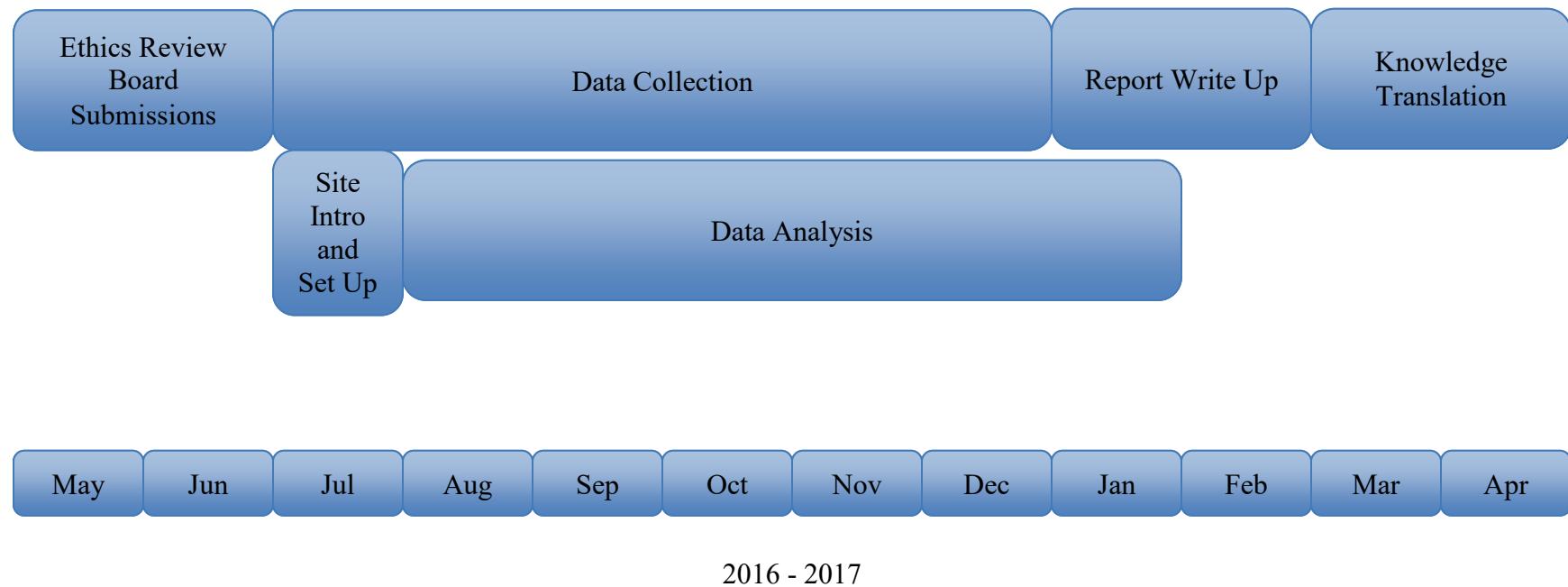
Hibbard, J. H., Mahoney, E. R., Stock, R., & Tusler, M. (2007). Do Increases in Patient Activation Result in Improved Self-Management Behaviors? *Health Services Research*, 42(4), 1443–1463. <http://doi.org/10.1111/j.1475-6773.2006.00669.x>

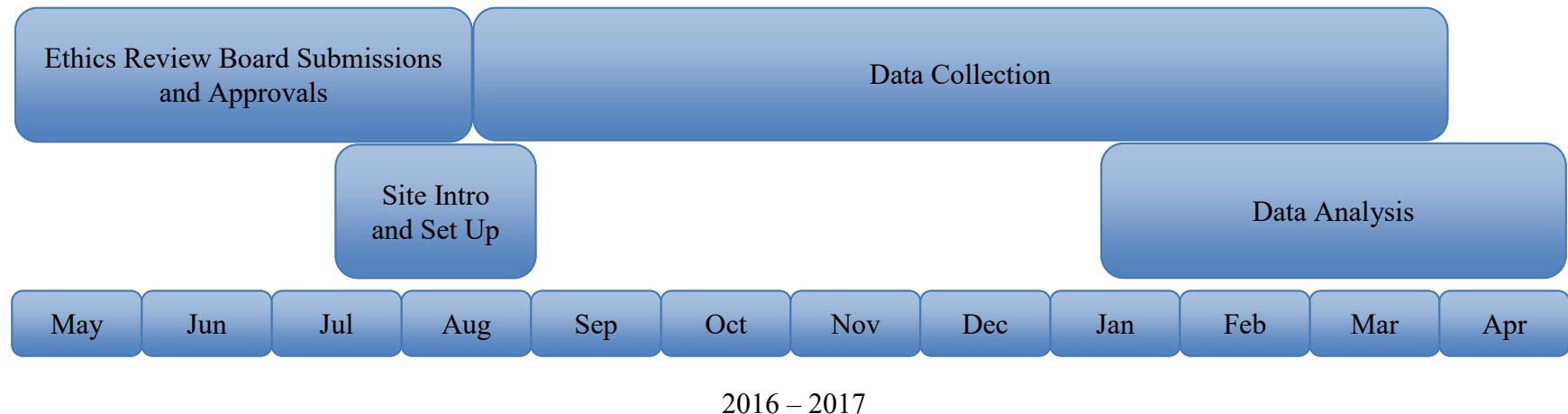
Hung, M., Carter, M., Hayden, C., Dzierzon, R., Morales, J., Snow, L., ... Samore, M. (2013). Psychometric assessment of the patient activation measure short form (PAM-13) in rural settings. *Quality of Life Research*, 22(3), 521–529. <http://doi.org/10.1007/s11136-012-0168-9>

Marshall, R., Beach, M. C., Saha, S., Mori, T., Loveless, M. O., Hibbard, J. H., ... Korthuis, P. T. (2013). Patient Activation and Improved Outcomes in HIV-Infected Patients. *Journal of General Internal Medicine*, 28(5), 668–674. <http://doi.org/10.1007/s11606-012-2307-y>

Appendix B: Study Timeline

Proposed Study Timeline:



Actual Study Timeline:

Appendix C: Proposed Study Budget

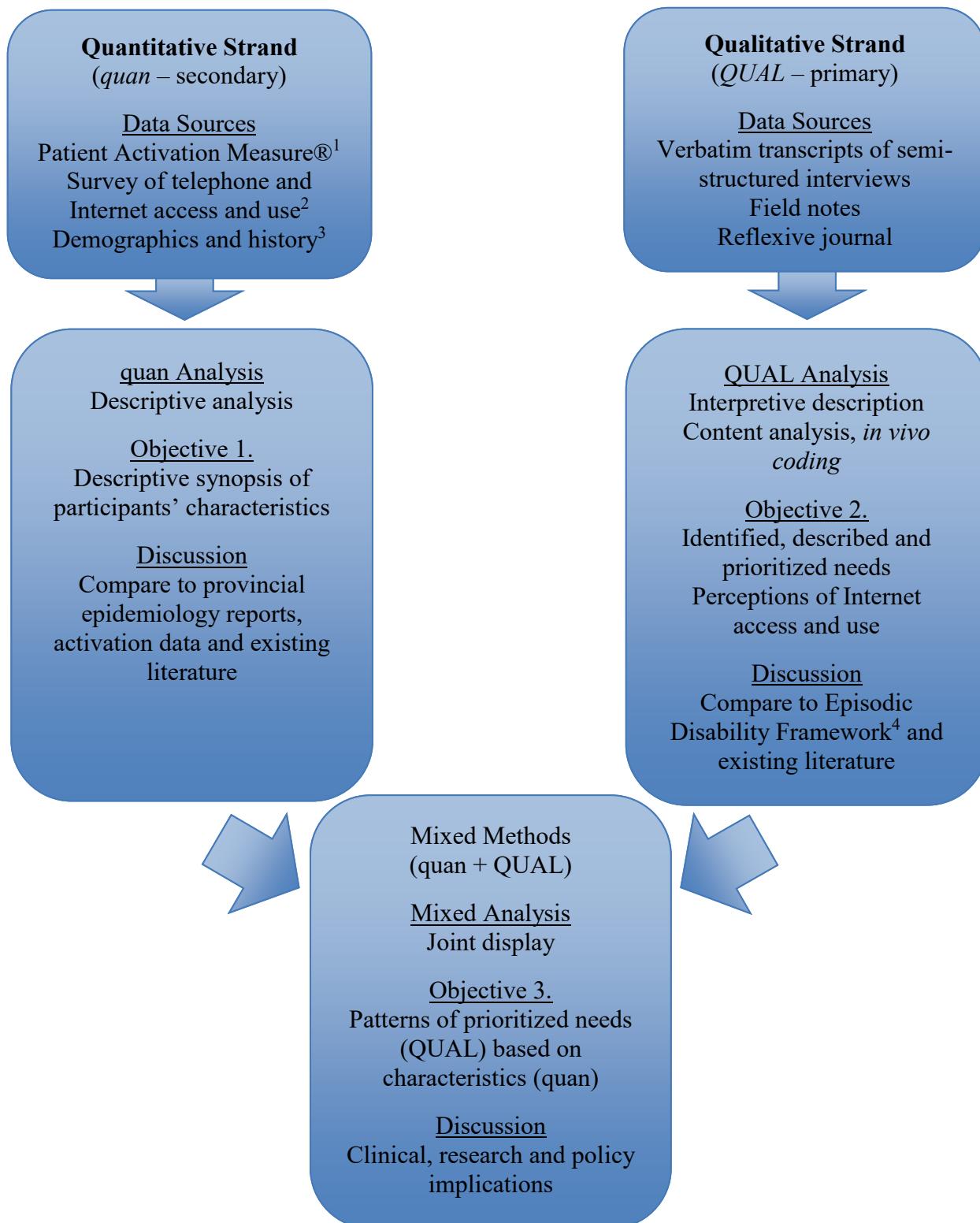
Budget – Total requested: \$5,623.60

Budget Item	Justification of expenditures	Amount
Personnel:		
1. Transcriptionist	A transcriptionist paid \$20/hour will require 4-5 hours to transcribe each hour of audio recording. Twenty-four, 1 hour interviews = approximately 24 hours of audio recordings x 5 hours transcription time = 120 hours of transcription x \$20/hour = \$2,400	\$2,400
Equipment:		
2. Phone adaptation for recording	An adapter to digitally record telephone interviews is required for data collection purposes = \$80	In-Kind
3. Digital recorder	Two digital recorders are required for in person interviews to ensure data is recorded = \$250 x 2	In-Kind
4. Nvivo software	NVivo software is required to manage and analyse qualitative data = \$170 at student rate, 12 month license	\$170
5. REDCap Access	Research Electronic Data Capture (REDCap) is required to collect and store demographics of participants in a secure manner. REDCap is a secure web application that captures data for research studies, and is designed to comply with PHIA & FIPPA regulations. It is highly secure and recommended for managing health information data that needs to be linked with participant identifiers for analysis. Implemented by the George & Fay Yee Centre for Healthcare Innovation with the University of Manitoba, Faculty of Health Sciences. \$300 for 3-year minimum period to access required software and security token.	\$300
Honorariums:		
6. Compensation for time and resources	Participants will be compensated for time (approximately 3 hours to review consent, complete questionnaires, participate in qualitative interview and review summaries for member checking), and incidental resources spent participating (e.g., parking for in-person interviews, long distance cell phone time for telephone interviews), at a flat	\$1,440

	rate of \$60/participant x 24 participants = \$1440	
Other:		
7. Long distance phone calls by interviewer	24 x 1 hour of interview + interview set-up + information calls + follow-up calls = approximately 48 hours of telephone calls @ \$.05/minute = \$144	\$144
8. PAM® Research License	Research license for graduate study purposes to use copyrighted Patient Activation Measure® (PAM®) for one year, with up to 250 participants, according to license agreement terms = \$0.	\$0
Supplies:		
9. Postage stamps	Postage for mailing study 24 consent forms + 24 postage paid return envelope = 48 stamps @ \$0.85/each = \$40.80 Postage for mailing 24 summary reports for member checking + 24 postage paid return envelopes = 48 stamps @ \$0.85/each = \$40.80	\$81.60
Knowledge Translation:		
10. Stakeholder Dissemination and Exchange Sessions	Meeting space for non-profit group, \$29/1,001-2,000 square feet a day, for 2 days = \$58 Lunch, snacks and coffee, for 30 people, \$20/person = \$600 Meeting supplies, pens, markers, paper, etc. = In-Kind	\$58 \$600 In-Kind
11. Conference presentation of proposal	Attend and present poster presentation of study proposal at the Annual Canadian Association for HIV Research Conference, Winnipeg, Manitoba. Student registration fee = \$275, plus 19.375 ft ² poster at \$8/ft ² = \$155	\$275 \$155
Total	\$5,623.60	

Additional funding for post-study conference fees, associated travel costs and other dissemination will be sought.

Appendix D: Study Diagram



Appendix E: Access and Use of the Internet for Personal Use

The following questions are about your access and use of the Internet for personal use. Please circle your answer for each question.

Telephone

TE1. Do you have a telephone?

- a) No
- b) Yes, a land line only
- c) Yes, a cellular phone only
- d) Yes, both a land line telephone and cellular phone

TE2. Can you use the Internet with your phone?

- a) Yes
- b) No
- c) I don't know

Use

US1. How often do you use the Internet for personal use?

- a) Never → Proceed to alternate survey regarding non-use
- b) Less than once a year
- c) Yearly
- d) Monthly
- e) Weekly
- f) Daily
- g) Many times a day

US2. When did you start using the Internet for personal use? (Record approximate year/month started using the Internet for personal use; convert to years/months.)

Date: _____

Months of Use: _____

US3. What device(s) do you use to access the Internet for personal use? Circle the letter of all that apply to you.

- a) Desktop computer
- b) Laptop
- c) Smart phone
- d) Smart TV or gaming system
- e) Tablet (touch screen device)
- f) E-book reader
- g) Other _____

US4. Where do you mainly access the Internet for personal use? Circle one.

- a) Home
- b) Work
- c) School
- d) Public Library
- e) Friend's or relative's home
- f) Government office or health centre
- g) Place in my community offers Wireless Internet Service (Wi-Fi) _____
- h) In my community using a portable device and a service I pay for (e.g. 3G network access with cellular phone or tablet)
- i) Other _____

US5. Where else do you access the Internet for personal use? Circle the letter of all that apply to you.

- a) Home
- b) Work
- c) School
- d) Public Library
- e) Friend's or relative's home
- f) Government office or health centre
- g) Place in my community offers Wireless Internet Service (Wi-Fi) _____
- h) In my community using a portable device and a service I pay for (e.g. 3G network access with cellular phone or tablet)
- i) Other _____

Performance Expectancy

PE1. I find the Internet useful in my daily personal life.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

PE2. Using the Internet for personal use helps me accomplish things more quickly.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

PE3. Using the Internet for personal use increases my productivity.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

Effort Expectancy

EE1. Learning how to use the Internet for personal use is easy for me.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

EE2. My interaction with the Internet for personal use is clear and understandable.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

EE3. I find the Internet for personal use is easy to use.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

EE4. It is easy for me to become skillful at using the Internet for personal use.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

Social Influence

SI1. People who are important to me think that I should use the Internet for personal use.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

SI2. People who influence my behaviour think that I should use the Internet for personal use.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

SI3. People whose opinions that I value prefer that I use the Internet for personal use.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

Facilitating Conditions

FC1. I have the resources necessary to use the Internet for personal use.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

FC2. I have the knowledge necessary to use the Internet for personal use.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

FC3. The Internet is compatible with other technologies I use for personal use.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

FC4. I can get help from others when I have difficulties using the Internet for personal use.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

Hedonic Motivation

HM1. Using the Internet for personal use is fun.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

HM2. Using the Internet for personal use is enjoyable.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

HM3. Using the Internet for personal use is very entertaining.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

Price Value

PV1. The Internet is reasonably priced for my personal use.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

PV2. The Internet for my personal use is a good value for the money.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

PV3. At the current price, the Internet provides good value for my personal use.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

Habit

HT1. The use of the Internet for my personal use has become a habit for me.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

HT2. I am addicted to using the Internet for personal use.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

HT3. I must use the Internet for personal use.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

Behavioural Intention

BI1. I intend to continue using the Internet for personal use in the future.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

BI2. I will always try to use the Internet for personal use in my daily life.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

BI3. I plan to continue to use the Internet for personal use frequently.

- a) Strongly disagree
- b) Disagree
- c) Slightly disagree
- d) Undecided
- e) Slightly agree
- f) Agree
- g) Strongly agree

The items under Performance Expectancy, Effort Expectancy, Social Influence, Facilitating Conditions, Hedonic Motivation, Price Value, Habit, and Behavioural Intention are adapted and used with permission from: Venkatesh, V., Thong, J., & Xu, X. (2012). Consumer acceptance and use of information technology: Extending the unified theory of acceptance and use of technology. *MIS Quarterly*, 36(1), 157-178.

Access and Use of the Internet for Personal Use: Alternate Questions for Participants Not Using the Internet for Personal Use

NO1. You stated you never use the Internet for personal use. What are your reasons or why don't you use the Internet for personal use?

NO2. Have you ever used the Internet for personal use in the past?

- a. Yes
 - b. No
 - c. I don't know

If yes, why did you stop using the Internet for personal use? _____

NO3. Is there anything else you would like to say about using or accessing the Internet for personal use?

Date: _____

Appendix F: Demographics and History Questionnaire

1. What is your age?

Number of years _____

2. Are you a Canadian citizen?

- a. Yes
- b. No

If you answered Yes, please skip to question 4.

3. Are you new to Canada, (i.e., arrived as a landed immigrant or refugee within the past 5 years)?

- a. Yes
- b. No

If you answered Yes, what country were you born in? _____

4. Do you consider yourself to be an Indigenous or Aboriginal person (i.e., North American First Nations, Métis, Inuk/Inuit, Status or Non-Status)?

- a. Yes
- b. No
- c. Don't know

5. What is your highest level of education completed?

- a. No school
- b. Some school
- c. High school diploma
- d. College/technical degree
- e. Bachelor's degree
- f. Master's degree
- g. Doctoral degree

6. What is your current main activity?ⁱ

- a. Working a paid job or business
- b. Looking for paid work
- c. Going to school
- d. Caring for family members
- e. Household work
- f. Retired
- g. Maternity, paternity or parental leave
- h. Long term illness
- i. Volunteering
- j. Other _____

7. How many children (under 18 years of age), live in your home? _____

8. How many adults live in your home besides you? _____
9. What is your marital status?
 - a. Never married
 - b. Married (not separated)
 - c. Separated but still legally married
 - d. Common-law
 - e. Divorced
 - f. Widowed
10. What is your yearly household income (i.e., income you contribute or have access to for costs of living)?
 - a. Less than \$10,000
 - b. \$10,000 – 19,999
 - c. \$20,000 – 39,999
 - d. \$40,000 – 59,999
 - e. \$60,000 – 79,999
 - f. \$80,000 – 99,999
 - g. \$100,000 or more
 - h. Don't know
11. What was your assigned sex at birth?
 - a. Male
 - b. Female
 - c. Undetermined
 - d. Don't know
12. Do you consider yourself to be trans (transgender, transsexual, or a person with a history of transitioning sex)?ⁱⁱ
 - a. Yes
 - b. No
 - c. Don't know
13. What gender do you currently live as in your day-to-day life?ⁱⁱ
 - a. Male
 - b. Female
 - c. Sometimes male, sometimes female
 - d. Other

14. What do you consider to be your sexual orientation?

- a. Heterosexual
- b. Gay
- c. Lesbian
- d. Bisexual
- e. Transgender
- f. Two-spirit
- g. Queer
- h. None of the above
- i. Don't know

15. Have you ever used a needle to inject or be injected with a drug not prescribed by a doctor?ⁱ

- a. Yes
- b. No
- c. Don't know

16. In general, would you say that your health is...ⁱ

- a. Excellent
- b. Very good
- c. Good
- d. Fair
- e. Poor

17. How many years have you been diagnosed with HIV?

Number of years _____

18. How well controlled is your HIV?

- a. Well controlled
- b. Somewhat controlled
- c. Not well controlled
- d. Don't know

19. Are you taking highly active antiretroviral therapy (HAART)?

- a. Yes
- b. No

If Yes, for how many years? _____

20. Do you have any other health condition(s) or diagnoses?

- a. Yes
- b. No
- c. Don't know

If Yes, what one(s)? _____

21. Do you have a regular health care provider in your community (a health professional you regularly see or talk to when you need care or advice about your health)?ⁱ

- a. Yes
- b. No

If Yes, skip to question 23.

22. What are your reasons for not having a regular health care provider?ⁱ

- a. Do not need one, but have a usual place to go for care
- b. No one available in the area
- c. No one in the area is taking new patients
- d. Have not tried to find one
- e. Regular health care provider retired or left
- f. Other _____

Skip to question 24.

23. Is your regular health care provider a...?ⁱ

- a. Family doctor or general practitioner
- b. Nurse (e.g. at local nursing station)
- c. Medical specialist such as a cardiologist or an oncologist
- d. Nurse practitioner
- e. Other _____
- f. Don't know

24. Do you have a health care provider specifically for your HIV?

- a. Yes
- b. No

If Yes, skip to question 26.

25. What are your reasons for not having a health care provider specifically for your HIV?

- a. Do not need one, but have a usual place to go for care
- b. No one available in the area
- c. No one in the area is taking new patients
- d. Have not tried to find one
- e. HIV health care provider retired or left
- f. Other _____

Skip to the end of the questionnaire.

26. Is your HIV health care provider a...?

- a. Family doctor or general practitioner
- b. Nurse
- c. Medical specialist (e.g. infectious diseases specialist)
- d. Nurse practitioner
- e. Other _____
- f. Don't know

27. Where is your HIV health care provider located?

- a. In my community
- b. In another community, _____, I drive or am driven to appointments
- c. In another community, _____, I take a plane to appointments
- d. Other: _____

Thank you for completing this form.

ⁱ Question 6, 15-16, 21-23 retrieved from Statistics Canada

<http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3226>

ⁱⁱ Questions 12 and 13 retrieved from: Institute of Gender and Health, Canadian Institutes of Health Research. (2012). *What a difference sex and gender make: A gender, sex and health research casebook* (p. 64 & 65). Ottawa, ON: Canadian Institutes for Health Research.

Appendix G: Screening Questions for Inclusion in Research Study

Title: Perspectives of people living with HIV: Activity and participation needs when living at a distance from specialized services

Read the following to interested potential participants, in person, or by telephone:

Thank you for your interest in participating in the study: Perspectives of people living with HIV: Activity and participation needs when living at a distance from specialized services.

I need to ask you 5 questions to make sure that it is suitable for you to take part in this study:

*(Circle the potential participants response)

Q1: Are you 18 years or older? Yes No

Q2: Do you live outside Winnipeg, but within the Province of Manitoba? Yes No

Q3: Have you been diagnosed with HIV for 6 months or longer? Yes No

Q4: Do you speak and understand English? Yes No

*The principal investigator will use clinical judgment while reviewing consent with each participant to make the final determination as to their sufficient understanding of English to participate.

Q5: Are you legally in charge of making your own medical decisions? Yes No

*In addition to participant self-report, the principal investigator will use clinical judgment and observation with regards to this question. If any concerns, Manitoba HIV Program staff will be consulted for the protection of the client.

Eligible to participate Yes No

Rationale: _____

Initials: _____

Date: _____

Appendix H: Consent Form

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

Title of Study: Perspectives of people living with HIV: Activity and participation needs when living at a distance from specialized services

Principal Investigator: Alexandria Simms, OT Reg. (MB)
Department of Occupational Therapy, University of Manitoba
R106-771 McDermot Avenue, Winnipeg, MB, R3E 0T6
Phone: (204) 480-1393 E-mail: Alexandria.Simms@umanitoba.ca

Co-Investigators: Gayle Restall, OT Reg. (MB), PhD, University of Manitoba

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your health care provider, friends or family before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

Purpose of Study

The purpose of this study is to develop an understanding of daily activity and participation needs for people living with HIV, outside of Winnipeg, in Manitoba. We want to learn about barriers, resources and possible solutions that will help people living with HIV participate in home, school, work, and leisure activities. We also want to understand the best ways for services to be delivered. We will be recruiting approximately 16 to 24 people living with HIV to participate in this study.

Study Procedures

If you participate in this study you will be asked to do following:

- Answer a questionnaire that will take approximately 10 minutes to complete. The questionnaire will ask you for basic demographic and health history information. This information will tell us about the diversity of people who are taking part in the study.
- Answer a questionnaire about your access and use of the Internet that will take approximately 10 minutes to complete. The questionnaire is about how easy or hard it is for you to access the Internet for personal use, and if it is helpful to you.
- Answer a questionnaire, the Patient Activation Measure (PAM-13) that will take approximately 5 minutes to complete. The PAM-13 is used to assess how a person feels about managing their health.
- Participate in a one-hour individual interview by telephone or in person. The principal investigator will conduct the interview. During the interview you will be asked about your needs and use of services that help you do the activities you need and want to do. The interviewer will also ask about resources, barriers, and your opinions about the best way to meet the needs for people living with HIV in Manitoba, outside of Winnipeg. The interview will be audio recorded and typed word for word. At that time any use of your

name will be removed and replaced by a code number. Audio recordings will be erased once a member of the research team has checked the written document.

- You may choose to be sent a written summary of the findings at the end of the study, which you can review, and send comments back to the research team. This helps ensure the results correctly represent what you and other participants shared.

During the study, you will be free to discuss any part of your life or health condition. You are free to not answer any of the questions or not discuss any of the issues you choose.

You can stop participating in this study at any time. However, if you decide to stop participating in the study, we encourage you to talk to the study staff first.

Risks and Discomforts

There should be no physical risks or discomforts associated with this study other than sitting and talking for at least an hour during the interview or while answering questionnaires.

The questionnaire forms you answer will be de-identified. This means that we will not use your name when we store or report any questionnaire information from this study.

When we analyze the information from your interview you will be de-identified. This means that we will not use your name or identifying information when we store or report any interview information from this study. Every effort will be made to protect and safeguard your privacy. However, there remains a potential risk of loss of privacy.

If you have any concerns or experience some distress as a result of the personal nature of the questions, you may discuss it directly with the interviewer, or see the contact information provided for free, confidential support services attached to this consent form.

Benefits

There may or may not be direct benefit to you from participating in this study. We hope the information learned from this study will benefit people living with HIV in the future.

Costs and Payment for Participation

If you participate in an interview you will receive \$60.00 cash or gift card to assist you in covering costs such as your time, telephone minutes and transportation. There are no other costs to you to participate.

Confidentiality

Information gathered in this research study may be published or presented in public forums. However, your name and other identifying information will not be used or revealed. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law.

In order to use the Patient Activation Measure® (PAM®), we have agreed to share the anonymous data with the copyright holders of the survey at the University of Oregon. They will use the information we submit to help assure the ongoing quality and accuracy of the survey itself, to improve the survey for healthcare providers and patients. You will not be able to be identified by the information that is shared. The copyright holders will not change the data, share it with other organizations or publish results from your data. The data to be shared includes:

- 1) The number of participants who completed the PAM®
- 2) Date the PAM® was completed, coded identifier, answers to each of the PAM® questions, total PAM® score and calculated Patient Activation Level.

All records will be kept in a locked secure area and only investigators will have access to these records. Records will be destroyed 5 years after closure of the study. The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes. If any of your research records need to be copied to the University of Manitoba Health Research Ethics Board, your name and all identifying information will be removed. No information revealing any personal information such as your name, address or telephone number will leave the University of Manitoba except as necessary to transport information to and from the site of in-person interviews.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your ability to receive health services at the Health Sciences Centre, Nine Circles Community Health Centre or elsewhere. You are not waiving any of your legal rights by signing this consent form or releasing the investigators from their legal and professional responsibilities.

Questions

You are free to ask any questions that you may have about the study and your rights as a research participant. If any questions come up during or after the study, please contact the principal investigator, Alexandria Simms, at 204-480-1393. For questions about your rights as a research participant, you may contact the University of Manitoba, Bannatyne Campus Research Ethics Board Office at 204-789-3389.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss this research study with Alexandria Simms or her study staff. I have had my questions answered by them in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Manitoba Research Ethics Board, for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

I agree to participate in this study..... Yes No

I agree to be contacted for follow-up in relation to this study..... Yes No

I agree to be sent a summary of study results prior to results being finalized..... Yes No

Participant signature _____ Date _____
(day/month/year)

Participant printed name: _____

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent

Printed Name: _____ Date _____
(day/month/year)

Signature: _____

Role in the study: _____

SUPPORT SERVICES

Sexual Health Info Line

Free and confidential information and referrals to callers from Manitoba.

- Answer questions and provide information about HIV
- Help provide connections to community resources
- Mail out resources on request

Hours: Monday – Friday 9:30 a.m. to 5:00 p.m.

Phone: 204-945-2437

Toll Free: 1-800-782-2437

Klinik Crisis Line (24 hours)

Phone: 204-786-8686

Toll Free: 1-888-322-3019

TTY: 204-784-4097

Manitoba Suicide Line (24 hours)

Toll Free: 1-877-435-7170

Appendix I: Semi-Structured Interview Guide

Introduction:

- Privacy, confidentiality and voluntary participation
- Audio-recording
- Answer only those questions you feel comfortable answering – can skip any you like

1. We are interested in learning about the daily needs of people living with HIV in relation to making it easier to participate in activities at home, work, school, or in leisure areas.

a. What activities do you currently participate in at home, work, school, or in leisure areas?



b. What activities would you like to participate in that you are not able to at the present time?

c. What makes it difficult to participate in these activities?

(Prompt: think of personal, physical, social, and emotional barriers in daily life. Stigma? Can you describe a time or situation you experienced difficulty?)

d. What would make it easier to participate in these activities?

(Prompt: services or supports?)

2. What kind of supports have you used in the past to help you to participate in these activities?

(Prompt: health or social supports? Formal and informal supports, rehabilitation services like OT, PT, other?)

a. What has worked for you in the past? Why?

b. What has not worked for you? Why?

3. We want to hear from you about:

a. What types of services would you like to see developed and what would you hope to get out of them

(Prompt: what outcomes are important to you?)

b. Who would you like to provide the services?

(Prompt: professionals, people, both?)

c. Who should be included?

d. Where would you like these services to be provided, and why?

(Prompt: home, community, specific location? What makes this a good location?)

- e. How should services be provided?
(Prompt: in-person, by telephone, by Internet, etc.?)
 - f. When should services be provided?
(Prompt: time of day, length of time after diagnosis?)
4. What would make it easier for you and others with HIV to use these services?
 5. What would make it more difficult for you and others with HIV to use these services?
 6. What recommendations do you have about how to promote the use of services that aim to make it easier to participate in activities at home, work, school, or in leisure areas?
 7. What do you think about using the telephone or Internet to access health services or supports that aim to make it easier for you to participate in activities?
(Prompt: Tell me about...Experiences with technology? Barriers and concerns? Benefits? The "why" behind survey responses, e.g. why or why not the Internet is useful in your daily life?)
- 8. What is the most important thing we discussed today? What is the second most important thing we discussed? What is the third most important thing we discussed?
[Record needs in priority, 1, 2 and 3. Review with participant for accuracy.]

First: _____

Second: _____

Third: _____

9. Is there anything else you would like to add?
