

EXPLORING INCREASED HIV PROGRAM DELIVERY IN NORTHERN ALBERTA

By

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**ABSTRACT**

As a community-based AIDS service organization, HIV North Society plays a key role in providing programming and supports for persons at risk or living with HIV in a vast, primarily rural region of Northern Alberta. This thesis examines the question: How can HIV North Society use collaborative strategies to increase and sustain the delivery of programming within Northern Alberta? The action research was performed utilizing a mixed-methods approach, which included an online survey and conversation café. Participants included a select sampling of funders, board members, community members, and persons living with HIV. In accordance with Royal Roads University ethics requirements, this research was conducted with the greatest degree of care and ethical consideration of participants. The research results suggest that there is potentially much value in new collaborative actions to increase program delivery. The new collaborative actions focus on shared vision, community capacity building, and education, for a collective impact.

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## CHAPTER ONE: FOCUS AND FRAMING

We are just at the beginning of an era of essential partnerships alliances, and coalitions. We are learning to build community beyond the walls of the organization, with the same kind of initiative and energy we have used in building the organization within the walls. (Hesselbein, 2011, para. 14)

Providing HIV awareness, education, prevention, and support services within a region that has an area of approximately 150,000 km<sup>2</sup> (City of Grande Prairie, 2008) is a daunting task (see Appendix A for a map of this region). This is the reality for HIV North Society (HIV North), an AIDS Service Organization (ASO) within the Province of Alberta. This challenge of providing services to dispersed populations grew exponentially when the HIV North region expanded as of November 2011 to a combined area of approximately 190,000 km<sup>2</sup> with the inclusion of the Municipality of Wood Buffalo.

A founding member of HIV North (and the organizational sponsor of this study) has identified that in its 25 years of existence, budget, human relations, and organizational leadership constraints all contribute to restrictions of the delivery of services within HIV North's regional boundaries (G. Pellerin, personal communication, August 4, 2011).<sup>1</sup> These constraints are further perpetuated by the constant changing demographics of communities, populations requiring services, and a revision of geographical health zones. HIV North has concentrated service delivery to the larger communities within the region and provided programming to other communities on a request basis. Pellerin contended there remain many smaller communities within the HIV North region where supports and programming are lacking, yet there is no known infrastructure to support initiating, increasing, and sustaining services to these communities.

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<sup>1</sup> All personal communications in this document are used with permission.

Prior to this study, the topic of reaching these communities continually came forward, but no actions had been taken to rectify the needs.

As Executive Director of HIV North for the past 5 years, I have actively participated in one full cycle of funding, programming, evaluation, and have experienced the frustrations that have led to inconsistent program delivery within the region. Organizational change is required to ensure quality programming is delivered to the entire region on an ongoing basis, but what kind of change is yet to be determined.

Coghlan and Brannick (2010) spoke to the steps of learning as “attending to experience . . . stand back . . . and inquire” (p. 21). As a relative newcomer to HIV North, I have attended to the organizational experience by bringing a new perspective to the possibilities within the organization that await us if we are able to learn from past experiences. I have spent the first 2 years largely standing back and observing and now in this research project, I take the steps to inquire. My role within this inquiry was one of insider researcher<sup>2</sup>, with the ability to implement the recommendations from the inquiry as directed by my Board of Directors.

The inquiry question I proposed in this study was: How can HIV North Society use collaborative strategies to increase and sustain delivery of programming within Northern Alberta? Subquestions included to support the inquiry were:

1. What collaborations currently exist?
2. What could HIV North do to increase collaboration and achieve outcomes?
3. What collaborative opportunities are already available to act upon?

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<sup>2</sup> Note that there are a number of ethical questions involved in insider research, which I address in Chapter 3.

### **Significance of the Inquiry**

When stakeholders collectively investigate their situation, they build a vision that is consensual of their world (Stringer, 2007, p. 11). This inquiry sought to understand the complexities of providing programming and supports to geographically large regions and identified potential collaborative opportunities to increase and sustain programming in diverse communities within the region.

The key stakeholders of this inquiry were the HIV North Board of Directors, Executive Director, front-line team, and the community members who are served, including persons living with HIV and those at risk of contracting HIV. The board determines strategic direction, including organizational change, and tasks the Executive Director and front-line team with implementation.

Providing and sustaining programming within large regions is a challenge faced by many ASOs in the province. The inquiry benefits stakeholders by providing insight that could enable ASOs to provide increased, sustainable programming to a geographically dispersed rural area, as well as inform, where possible, supports and health promotion strategies across the province to address the increasingly complex needs of people living with HIV/AIDS<sup>3</sup>, and those at risk.

Should the inquiry not have been addressed, there is a risk that many northern communities within the Province of Alberta will not be afforded the opportunity of HIV awareness, prevention, education, care, and support programming, which could prevent further

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<sup>3</sup> HIV is the acronym for human immunodeficiency virus; AIDS is the acronym for acquired immune deficiency syndrome. A person may live with HIV without ever having AIDS.

increase in HIV infection rates. Persons living with HIV/AIDS (PHAs)<sup>4</sup> within remote communities would continue to have the potential to remain isolated with their disease without adequate supports. The inquiry provided insight that could assist in increasing programming. It also provided additional information on community needs. The findings will assist in determining the next steps for HIV North.

### **Organizational Context**

HIV North is a nonprofit ASO incorporated in 1987 as the South Peace AIDS Council (S. Dunfield, personal communication, July 7, 2011). The organization was developed in response to the AIDS epidemic, which was spreading across the country in the 1980s in particular, in an effort to provide awareness, education, and prevention to individuals within the region (HIV North Society, 2007). Both the provincial Alberta Health and Wellness and the federal Public Health Agency of Canada provide cycles of 3-year core funding to ASOs within the province through the Alberta Community HIV Fund (Canadian Public Health Association, 2005).

As a nonprofit organization, HIV North is currently structured with a governing Board of Directors who collectively hire one individual, the Executive Director. In this role, my job is to implement the operations of the organization following the strategic direction of the Board. This includes identifying and accessing outside funding sources through proposals. I currently lead a front-line team of 10 staff, to provide services throughout the HIV North region in realizing the vision and mission of the organization. HIV North has one main office in Grande Prairie and

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<sup>4</sup> PHA is an abbreviation for persons living with HIV or AIDS and is used synonymously with PLW, which is an acronym for persons living with.

satellite offices in both Peace River and Fort McMurray, both of which are currently operating with one onsite employee in each.

HIV North's mission is "to lead Alberta's north in the fight against HIV through education, innovation, advocacy and collaboration" (HIV North Society, 2012, p. 2). The organization's vision is "a world without AIDS" (HIV North Society, 2012, p. 2). It is this global vision and organization-specific mission that prove organizationally challenging to uphold given the size and distance the region covers, as well as budget and staffing constraints. For the past 25 years, HIV North initially served the northwest region of Alberta, which encompassed approximately 19% of Alberta. Grande Prairie, a city of 55,032 (Statistics Canada, 2012b, p. 16), is the hub of HIV North's activities; however, this region includes 84 other towns, villages, and hamlets that are also served on an as-requested basis (HIV North Society, 2009).

Recently, the Alberta Community HIV Policy and Funding Consortium requested HIV North increase its regional services to include the Regional Municipality of Wood Buffalo, the largest regional municipality in Canada, situated in the northeast region of Alberta (Regional Municipality of Wood Buffalo, 2011, p. 6). This increased the HIV North region by 68,484 km<sup>2</sup>, resulting in a service delivery region encompassing approximately one half of the Province of Alberta, primarily in the rural north. The Regional Municipality of Wood Buffalo has a total population of 119,496 and is inclusive of the City of Fort McMurray, nine other communities, 24 First Nation Reserves, and a shadow population of "temporary residents . . . employed by an industrial or commercial establishment" (Regional Municipality of Wood Buffalo, 2012, p. 142) estimated at 39,271.

In 2010, the third largest proportion of newly diagnosed HIV cases was in the North Zone of Alberta, and 31% of newly diagnosed cases in First Nations population were also in the North Zone (Alberta Health and Wellness, 2011). HIV North provides service in much of this North Zone, as indicated on the map in Appendix A.

### **Systems Analysis of the Inquiry**

Oshry (2007) stated, “In all systems there is a story that unfolds, a history that has shape, movement, pattern and direction” (p. 34). The global response to HIV/AIDS has grown in scope and complexity since the early years of the epidemic when little was known about the disease. In Canada, a combined effort of governments, nongovernmental and community organizations, along with researchers, health professionals, PHAs and those most vulnerable to HIV are engaged in addressing the disease and the conditions that sustain the epidemic. This global response is a prime example of a system, which Meadows (2008) defined as an “interconnected set of elements that is coherently organized in a way that achieves something” (Chapter 1, “More Than The Sum,” para. 1). This global response to HIV is interconnected with and has an impact on HIV North as an organizational system as described in Figure 1 below.

Within the Province of Alberta, there is a complex network of community-based ASOs that provide programming, services, and support in a variety of ways within differing communities and regions. Each ASO responds to the unique needs of the communities they serve, rather than having one model of programming for all; the model addresses the different cultures and societal influences within each region. HIV North’s region of delivery is now the largest region covered by a single ASO within the province. The impact of the increased geographic distance within HIV North’s region and the vastly differing needs within the region

has created a level of complexity that has accelerated the need for this inquiry and a move toward sustainable delivery of programming to communities. Funding cycles, as described below, exacerbate this complexity.

In addition, epidemiological data of HIV infection rates directly influence the system of program delivery within the province, the country, and globally. Program delivery is critical in areas in which the incidence of newly reported positive infection is increasing and equally important in areas of prevalence. The system is also affected by the demographic of new HIV infections, such as those amongst Aboriginal people or persons from endemic countries. Programming must be adapted to fit the cultural needs of the target population, which has the higher incidence level in order to effectively reduce incidence. In my experience, the epidemiologic data is often the basis for many of the funding decisions, as resources are usually directed to communities and populations with the highest need.

Since 2001, program and support service delivery has been influenced by Alberta's unique funding model, in which the Alberta Health and Wellness and Public Health Agency of Canada pool resources for allocation every 3 years through the Alberta Community HIV Fund (Canadian Public Health Association, 2005). The Alberta Community Council on HIV holds this fund. Nonprofit organizations whose mandates are HIV/AIDS programming are able to apply for this 3-year funding.

The constraint of this funding cycle adds to the complexity of the challenge of addressing HIV/AIDS in a geographically dispersed area and has caused internal organizational challenges and problematic patterns that affect the system of ASO program delivery in Alberta. For instance, the uncertainty of whether or not the organization will have secure funding beyond 3

years translates into limiting employee contracts to yearly. A problematic pattern that often occurs is that the organization appears to flourish and establish growth creating what Senge (2006) referred to as a reinforcing feedback loop (p. 79) in program delivery during the first 2 years of its 3-year funding cycle. However, by the third year, the insecurity of future funding lends itself to reversal of this reinforcing loop, leading toward the turnover of staff, which then slows programming and creates a standstill. From a systems perspective, this 3-year funding model is a “limits to growth structure” (Senge, 2006, p. 96), which means that there is an initial spiral of success, yet this limitation “also creates inadvertent secondary effects (manifested in a balancing process) which eventually slow down the success” (p. 94). This problematic pattern was further reinforced by turnover in leadership of the organization. Access to stable financial resources is a significant current limiting factor for HIV North. This complex system within which HIV North resides is shown in Figures 1 and 2.

Community collaboration may provide the necessary balancing feedback needed to sustain the system of program delivery within rural regions and break out of the harm caused by this damaging funding cycle. With limited resources, in order to ensure supports are provided, this study suggests that program delivery can be accomplished through collaborative relationships with other service providers or community agencies. Hosting programming in existing agencies as well as sharing space and employees is already a reality for HIV North. This study researched how to expand this strategy of collaboration throughout the newly expanded region.



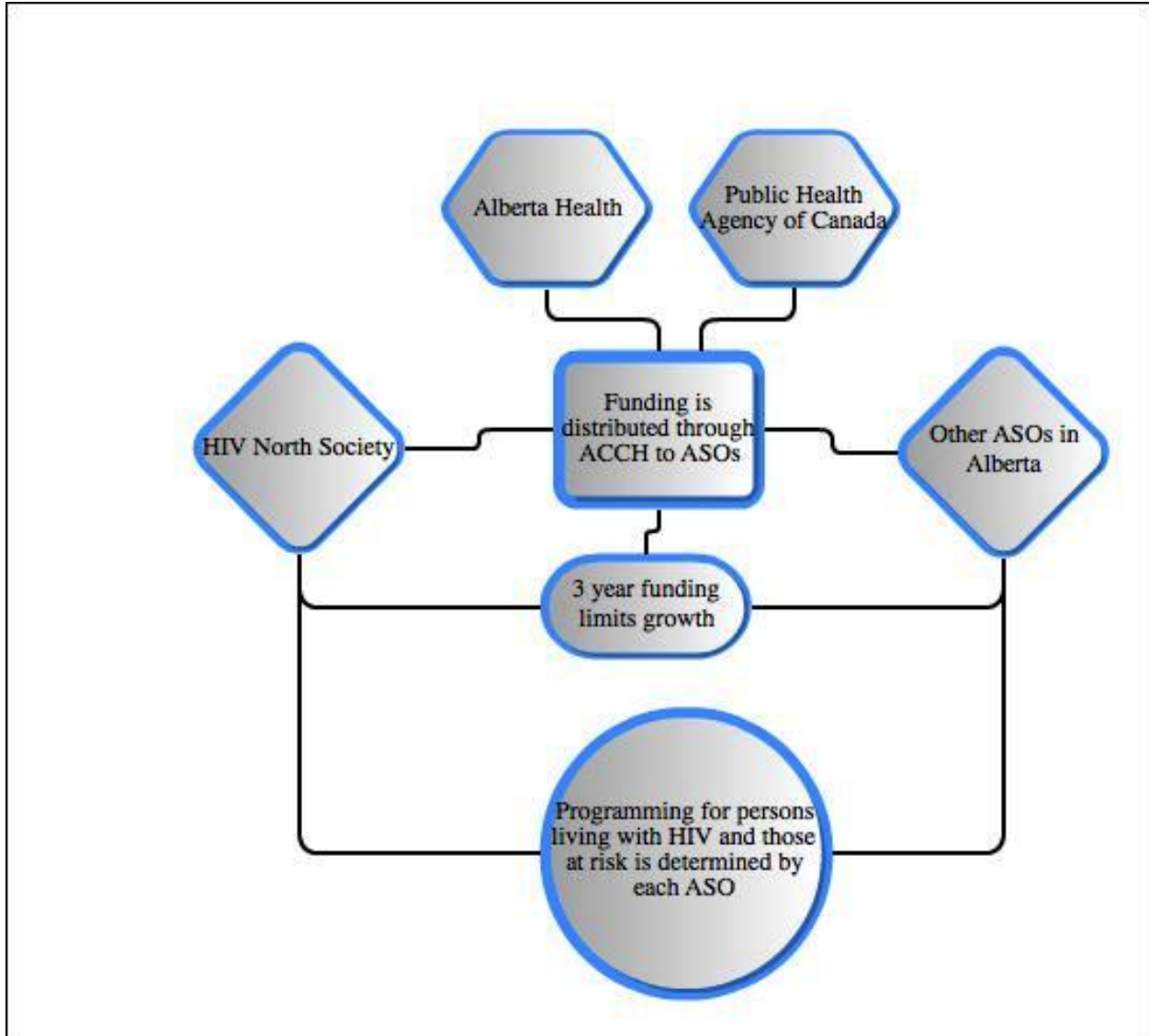


Figure 1. System of program delivery in Alberta.

Note. ACCH = Alberta Community Council on HIV; ASOs = AIDS Service Organizations.

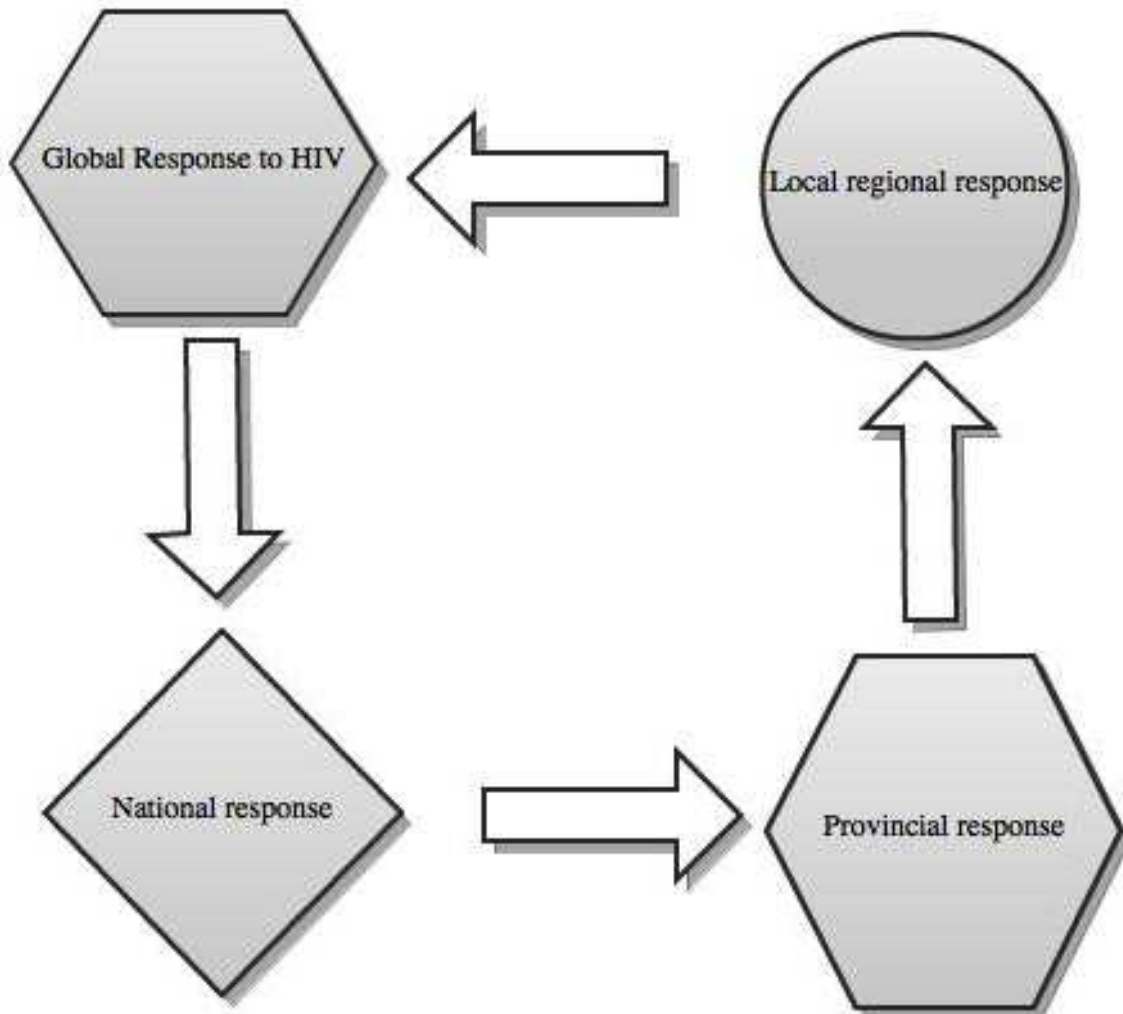


Figure 2. Response to HIV.

Senge (2006) stated, “To change the behavior of the system you must identify and change the limiting factor” (p. 100). He further noted that limiting factors continue to exhibit within the limits to growth structure, as each limitation is eliminated new limitations surface. While several limiting factors may be possible, in order to change the limiting factor previously identified as access to stable resources, through this study HIV North explored collaborative practices of other

organizations that deliver regional programming within the same expanded area and asked how further collaborative opportunities could increase and sustain programming needs?

### **Chapter Summary**

In this chapter I introduced the focus and framing of the study by relating the significance of the inquiry and providing an overview of the organizational context. In addition, I located this study within the broader context of the HIV/AIDS pandemic and demonstrated how multiple interconnected systems, particularly funding cycles, impact HIV North's ability to provide sustainable programming. Having introduced the parameters of this study, in Chapter 2, I review literature relevant to the issue of increasing and sustaining program delivery within Northern Alberta. I explore HIV/AIDS in rural communities and approaches to sustainable programming inclusive of but not limited to collaborative action and whole systems change.

## **CHAPTER TWO: LITERATURE REVIEW**

In this inquiry I examined the question: How can HIV North Society use collaborative strategies to increase and sustain delivery of programming within Northern Alberta? In order to better investigate this question, I investigated two bodies of scholarly literature, which are reflected in the two sections that comprise this chapter. The first section relates to health and HIV/AIDS service provision in rural communities. This first provides insight into the overarching context in which HIV North operates and discusses several factors affecting rural HIV programming more generally. The second section delves into the nature of sustainable programming in ASOs, including collaborative approaches and some of the challenges related to collaboration. The ideas of whole systems change, readiness for change, and resistance to change are also discussed.

I searched multiple databases through the use of Royal Roads Library Summon, including but not limited to ProQuest, SocIndex, CINAHL. I used an inclusive list of search terms both individually and in conjunction with each other: HIV/AIDS, community, programming, prevention, rural, collaboration, collaborative, action, strategies, and whole systems. Bibliographies from retrieved articles were examined for additional relevant sources of literature. To maximize the search I placed no restrictions on publication year, but restricted the search to online resources, available in English. As well I reviewed internal HIV North documents, journals to further identify published and unpublished literature.

I selected these topics for their relevance to the research question and also to provide further context for the findings this research question yielded. Each section is further outlined below.

## **Health and HIV/AIDS in Rural Communities**

As HIV North explores increasing HIV programming and sustainability within its vast region, it is essential to understand the realities HIV positive individuals face within rural communities in terms of access to prevention, screening, care, and support. This first section provides a foundation for understanding the challenges faced by PHAs living within rural communities and also by community-based organizations providing services within rural regions. This section covers three areas: (a) a definition of rural versus urban communities, (b) the challenges faced by people living with HIV in rural communities, and (c) the factors affecting program delivery to rural communities.

### **Defining rural versus urban**

The definitions of rural versus urban are varied and ever changing. Statistics Canada (2011) defined the concept of rural as an area with “fewer than 1,000 inhabitants and a population density below 400 people per square kilometer” (Statistics Canada, 2011, p. 1). This definition has been in place since the 1970s and sits in contrast to the definition of urban, which has been understood to be an area based on a population of 1,000 or higher and density of 400 or more persons per square kilometre (Statistics Canada, 2011). Statistics Canada (2011) replaced the term urban with the term population centre, in an attempt to improve interpretation of data and, for consistency, additionally created three specific subgroups of urban population centres: small, medium, and large.

In Alberta, 18% of the province is identified as rural area population and 44.8% of this rural area is within the North Zone (Health Region), the significance being that this is the region within which HIV North provides programming (Statistics Canada, 2012). The North Zone has

no large urban population centres, and only two medium population centres, Grande Prairie and Fort McMurray. The distance between communities such as Fort McMurray to the closest large urban population centre contributes to the isolation identified by many rural residents irrespective of their HIV status.

Some researchers identified poorer socioeconomic conditions, shorter life expectancy, and higher rates of disability and chronic illness in rural Canadians than in their urban counterparts (DesMeules & Pong, 2006; Mitura & Bollman, 2003). These authors further contended that shortages of local health care providers and access to specialized care is a significant factor for rural residents, leading to extended travel times for longer distances and a lack of health services (DesMeules, & Pong, 2006; Mitura, & Bollman, 2003). In this section I have provided an understanding of the region within which HIV North provides services and given context to the realities faced by residents within this primarily rural area.

### **Challenges faced by PHAs in rural communities**

Throughout the literature reviewed, the main challenges faced by PHAs who reside in rural communities were repeatedly identified as stigma and discrimination, lack of access to health care, and social isolation (Dalton, 2008; Groft & Robinson Vollman, 2007; Veinot, 2009; Veinot & Harris, 2011). The Canadian Public Health Association (2005) noted that stigma and discrimination is further increased should PHAs be identified with a specific community or culture, such as Aboriginal, gay men, those who use injection drugs, or persons from countries where HIV is endemic. Confidentiality and concerns around privacy or disclosure are a reality in rural communities and are identified in the literature as a significant challenge in rural areas of the United States, Canada, and Australia (Groft & Robinson Vollman, 2007; Poindexter, 2007;

Zuniga, Buchanan, & Chakravorty, 2006). Often fear of unwanted disclosure of status leads to the reluctance of PHAs to access available rural supports.

Access to health care for antiretroviral treatment requires PHAs to seek specialized medical care in larger urban population centres within the Province of Alberta. Many rural physicians are unable to provide information or support due to lack of training in HIV/AIDS care, including lack of knowledge of referral sources, which leads to increased cost and travel time for PHAs to access medical treatment and support (Groft & Robinson Vollman, 2007; Worthington, O'Brien, Myers, Nixon, & Cockerill, 2009).

Veinot and Harris (2011) conducted Canadian research that was consistent with American studies in their finding that residents in rural areas were less likely than urban dwellers to be knowledgeable about HIV/AIDS. Veinot and Harris further confirmed “rural Canadian communities are not yet fully understanding toward PHA’s [*sic*] who live in their midst” (p. 317). PHAs frequently deal with social ostracism and exclusion, poverty, homelessness, addictions, and lack of access to ASOs, all of which lead to further isolation. In addition to these socioeconomic factors that PHAs face, there are also a number of structural constraints on program delivery more generally, which I discuss in the next section.

### **Factors affecting program delivery**

Poindexter (2007) recognized that due to the constant changes in HIV health knowledge, populations affected, treatment options, “the HIV service ‘landscape’ is . . . like a volatile surging sea” (p. 9). The ever-changing demographic of PHAs presents challenges in programming in both rural and urban regions. ASOs in Canada are providing services to a wide variety of risk groups and target populations, which are often hard to reach. Target populations

have evolved and are diverse in gender, age, ethnicity, and income level (Chillag et al., 2002; Guenter et al., 2005).

Community-based ASOs are “typically resource poor” (Miller, 2001, p. 626) and they face many challenges in delivery of programming. Poindexter (2007) further asserted that “the temporary and contractual nature of funding” (p. 16), including both foundation and government grants, causes an unstable financial situation for ASOs, which results in spending valuable time on fund raising and proposal writing as opposed to providing the services that are the core of their work. This challenge directly relates to HIV North, as outlined in Chapter 1.

Chillag et al. (2002) categorized the key factors to service provision by ASOs as structural, sociocultural, and organizational, which were interwoven with individual client barriers. Structural barriers were identified as legal, policy, and economic issues; sociocultural barriers were identified as homophobia, stigma, distrust, and shame, while organizational barriers were high staff turnover, burnout, and lack of resources (Chillag et al., 2002, p. 30). While each of these factors can be found in both urban and rural settings, they are often exacerbated in rural areas, where staff recruitment can be difficult, added costs are often attached, and the sociopolitical climate for policies around such well-documented successful actions as harm reduction strategies or services such as needle distribution and recovery are often in opposition.

As Dalton (2008) noted, the sheer distance of providing programming to rural communities adds further strain to budgets and staffing. Dalton found travel time and distance between urban-based ASOs and rural communities requiring programming was a negative factor: travel and distance were “exhausting for some people” (p. 77) as ASOs strive to “provide



services to large geographical areas” (p. 77). In contrast, Eke, Mezoff, Duncan, and Sogolow (2006) saw “tailoring intervention” (p. 174) to respond to unique needs as a major positive factor in “ensuring successful HIV prevention interventions” (p. 174). HIV North has identified these very same barriers and positive factors in our programming within our large region over the past 10 years, which has led to our desire to identify further collaborative strategies.

Having reviewed the definitions of rural and urban, the challenges facing PHAs in rural communities and the factors affecting program delivery in this, I now provide review of the literature framing approaches to sustainable programming resources. This is inclusive of collaborative actions, challenges of collaboration, whole systems change and readiness for change.

### **Approaches to Sustainable Programming**

The ability of HIV North to continue to increase programming within the recently expanded region is limited at present. Exploration of potential approaches towards sustainable, increased programming is required. Two approaches, collaborative action and whole systems change, show great promise and are discussed further in the following subsections.

#### **Collaborative actions**

In order to determine collaborative actions, an understanding of the term collaboration is required. Review of the literature demonstrated a large variety of definitions of collaboration. Collaborations are often referred to as relationships, partnerships, coalitions, or networks; they are also considered as a process or institutional arrangement. A recurring theme among descriptions of what constitutes collaborations was working together towards a common goal or achievement (Austin, 2000b); Linden, 2002; Sowa, 2008; Takahashi & Smutny, 2001; Winer, &

Ray, 2011). For example, Winer and Ray (2011) stated, “Collaboration is a mutually beneficial and well defined relationship entered into by two or more organizations to achieve results they are more likely to achieve together than alone” (Part 1, The Story section, para. 38). Winer and Ray further utilized a metaphor of a journey to describe collaboration, travelling to a destination on a co-constructed road.

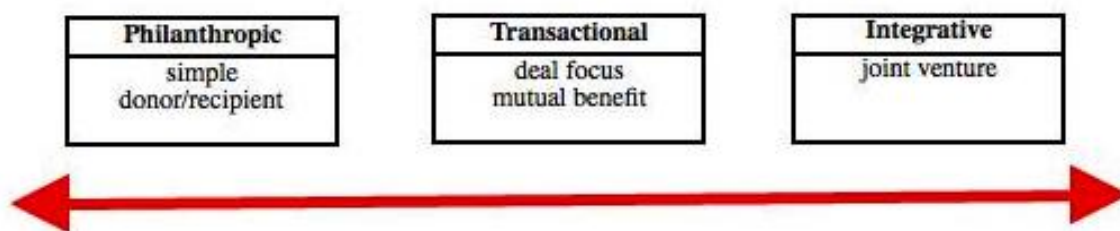
The literature I reviewed also identified “collective impact initiatives” (Corcoran, Hanleybrown, Steinberg, & Tallent, 2012, p. 26) as another distinct form of collaboration (see also Kania & Kramer, 2011). This collaborative strategy involves long-term commitments by groups of individuals across sectors to work on a common agenda to solve a specific problem. Each member contributes a “mutually reinforcing” (Corcoran et al., 2012, p. 19) activity and shares a common measurement process. This approach to collaboration focuses on relationships “between organizations and progress toward shared objectives” (Kania & Kramer, 2011, p. 39) and assists in bringing about large-scale change. Collective impact methods involve community first. The first step is to identify a goal, and to then assemble community members, inclusive of governments, faith communities, schools, businesses, philanthropists, and community leaders to discuss and explore ways to achieve that goal. This culminates in the creation of strategies and integrated activities each member can contribute, which allows them to achieve the goal (Hanleybrown, Kania, & Kramer, 2012).

Authors cited various reasons for initiating collaborations, inclusive of information sharing, funding, resources, strategic advantage, and coordination of service delivery (Austin, 2000b; Linden, 2002; Sowa, 2008; Sullivan & Skelcher, 2002). Linden (2002) stated that the “complexity of the major challenges facing our society and the blurring of many organization

boundaries” (p. 9) is the key factor in developing collaborative actions. This is concurrent with Austin’s (2000a) finding that “crisis can trigger collaboration” (p. 45). Austin (2000a) further supported the need to increase collaborative relationships to be more effective in dealing with the demands of our complex society. He additionally recommended that collaboration breach the gulf between non-profit agencies and public or for profit through cross sector partnerships (Austin, 2000a, p. 49).

Throughout the literature, relationships are noted as being crucial in the development and maintenance of collaborations. These relationships were placed in continuums, ranging from formal to informal. A description of formal collaborative relationships included use of terms of reference, memoranda of understanding, contracts, and formal description of duties, whereas informal relationships were more often described as collegial, friendships, or coworkers (Sowa, 2008; Takahashi & Smutny, 2001). Baker (2003) conceded that there exists a critical need to build collaborative relations for organizational success and further noted that reciprocity is key to developing collaborations (p. 13). They can occur across multiple sectors such as between nonprofits and government, business and nonprofit, interagency or interorganizational (Austin, 2000a, 2000b; Sowa, 2008; Takahashi & Smutny, 2001; Winer & Ray, 2011). Sowa (2008) established that within interagency collaborations there were multiple “variations . . . within a single form of collaborative service delivery” (p. 299). She further discovered within interagency collaborations, the more “that is shared between organizations . . . the more intense that relationship becomes and the more value is created by the collaboration” (Sowa, 2008, p. 318). Austin (2000b) noted that creating shared visioning allowed for collaborations to make more sustainable alliances.

An analysis of the literature reviewed also showed multiplicity in models or frameworks for collaboration. Sowa (2008) described three models (forms) of interagency collaboration: collaborative contract, capacity-building collaboration, and community-building collaboration. These forms were differentiated by commitment between organizations of shallow, medium, or deep, and then placed on a continuum portraying the impact of each. The community-building collaboration model was determined to have the greatest impact, as it had the “possibility of promoting future change” (Sowa, 2008, p. 316) while the “collaborative contract” (p. 316) was on the other end of the spectrum with minimal impact. In contrast Austin (2000b) described a “collaboration continuum” of three stages—philanthropic, transactional, and integrative (p. 20), which cross-sector relationships pass through (see Figure 3). On one end of the continuum spectrum is the philanthropic stage, which is primarily a simple relationship of donor and recipient. In the transactional stage, the focus is on the deal between the partners, and is mutually beneficial, whereas in the integrative stage, the relationship looks more like a “highly integrated joint venture” (p. 26) and is located on the opposite end of the continuum.



*Figure 3.* Collaboration continuum.

In summary, the multitude of interpretations found in the literature contributes to the incongruent use of the term collaboration within social systems. These differences may in turn result in challenges for collaborations as will be outlined next.

### **Challenges of collaborative actions**

Even with numerous strategic reasons for entering into a collaborative action, challenges to effective, successful collaborations exist. Winer and Ray (2011) described the factors that can negatively or positively affect collaboration as “ideology, leadership, power, history, competition, and resources” (p. 24). In contrast, Takahashi and Smutny (2001) categorized challenges into “three scales; contextual, institutional, and individual” (p. 142). Collaborations can fail when clarity of goals is lacking and/or when collaborative partners are not flexible when they are faced with change (Burke & Biggart, 2009, p. 728).

Maintaining open communication and trust was another overarching theme within the literature reviewed (Senge, Lichtenstein, Kaeufer, Bradbury, & Carroll, 2007; Takahashi & Smutny, 2001). Takahashi and Smutny (2001) noted that when collaborations were highly informal, miscommunication contributed to conflict, and conflict led to more miscommunication. Open communication, transparency, and trust as a requirement to build strong relations was reflected in Kouzes and Posner’s (2007) statement that a “climate of trust” (p. 295) is required to “facilitate effective long-term relationship” (p. 295). Fulton (2012) echoed this sentiment when he discussed the need to develop an “atmosphere of trust” (p. 14) in order to create successful, sustainable collaborations. Senge et al. (2007) remarked that effective communication requires respect, confidentiality, and listening (p. 47). Meanwhile, Austin (2000b) and Linden (2002) inferred that collaborative leaders should model open communication, which requires trust and trust must be earned.

In summary, the literature reviewed determined that although collaborations can be highly successful, there are also challenges associated with maintaining collaborative actions. In

the next section I explore whole systems change to assist in effective collaborations to provide increased sustainable programming.

### **Whole systems change**

Edwards, Rowan, Marck, and Grinspun (2011) asserted, “Whole systems change is nonlinear and cross-scale” (p. 10). In a world of complexities and interconnected systems, with cross-sector and multisector collaborations, effective change efforts require a whole system approach. While I describe the whole system as it applies to HIV North in greater detail in Chapter 5, in brief I am referring to change that is inclusive of individual organizations, community, regions, and government. Literature reviewed in this section suggested that a clear view of the entire system and insight into how systems interact provides opportunities to identify patterns. This whole systems approach further assists in the identification of “system leverage points” (Dattée & Barlow, 2010, p. 20) or “blockages” (Edwards et al., 2011, p. 4) that will hasten or slow down the change process (see also Senge, 2006). Wheatley (1999) stated, “From a systems consciousness, we understand that no problem or behaviour can be understood in isolation. We must account for dynamics operating in the whole system that are displaying themselves in these individual moments” (pp. 139–140). A clear map of the system is of great value when undergoing whole systems change such as that which will be required for sustainable programming in HIV North’s vast region.

Whole system change efforts focus on engaging players from all sectors across the system, in an effort to encourage involvement and commitment towards identifying solutions to complex issues. These change efforts further allow for whole system “learning and emergence”

(White, 2000, p. 169) as stakeholders work toward commonality. People who focus on bringing all sectors together can innovate together.

The literature I reviewed noted effective leadership at all levels within the system is essential to supporting whole systems change. Change requires leadership that is committed to the process and maintains supportive relations and interactions with multiple stakeholders (Burke & Biggart, 2009; Edwards et al., 2011; Weisbord, 2012; Zakariasen & Henderson, 2010). Yukl (2010) described “enabling leadership” (p. 521) as a method by which the process of facilitating is utilized to generate new and innovative solutions when multiple stakeholders are involved. Kouzes and Posner further expanded this view when they stated, “Leaders enable others to act not by hoarding the power they have, but by giving it away. Exemplary leaders strengthen everyone’s capacity to deliver” (p. 21). In summary, leadership during whole systems change is not required to be hierarchical; rather, collaborative or enabling leadership at all levels, in spite of the challenges outlined above, is considered to be most effective. In addition to directing their efforts toward collaborative, whole systems change, it is important for leaders to understand readiness for change, which I explain further in the next section.

### **Readiness for change**

Weiner (2009) described organizational readiness as a “multi-level, multi-faceted construct” (p. 2) and referred to members of organizations’ commitment to change and efficacy to implement the change. Throughout the literature reviewed, organizational readiness was identified as essential to successful organizational change (Austin & Claassen, 2008; Smith, 2005; Weiner, 2009). These literature sources also recognized the concept of unfreezing an organization, which originated in Lewin’s (as cited in Austin, Weiner, 2009) model of change, as

an initial key phase in creating change readiness. While Weiner (2009) contended that organizational readiness for change does not guarantee success for implementation of organization change (p. 7), encouraging organizational members to release the past status quo and embrace change as necessary mitigates potential resistance to change.

Smith (2005) identified three crucial steps in creating organizational readiness: creating urgency for change, communicating the message, and building a base for change. In contrast Weiner (2009) conceded creating urgency for change is sometimes useful but not when uncertainty is high. Weiner (2009) further suggested that highlighting discrepancies between desired organizational performance levels and the current state, and then creating a vision appealing to the future state can increase the value organizational members place on change.

The literature suggested that when taken together, the following factors play an important role in creating readiness for change: motivation, adequate resources, organizational climate and culture, and stakeholders' mindsets. When human needs, including financial, equipment, training and meaningful involvement are met before embarking on change process, increased readiness for change is created (Austin & Claassen, 2008; Weiner, 2009).

Block (2010) stated, "Change faces us with human questions, and dealing with them is dependent on a certain kind of integrity and willingness to participate in what we have chosen for the larger system" (pp. 313–314). As will be described in Chapter 4, this inquiry suggested that a thorough assessment of the willingness of the organization to change is required, in addition to leaders who can guide and encourage organizational members' participation in the process. In the final section of this literature review I provide more details on how such leaders can help to overcome resistance to change.



### **Understanding resistance**

Change is a reality for many organizations and it is met with two varying behaviours: adoption of the change or resistance. Resistance can be understood as a natural reaction; individuals use it to protect self-interests (at times unconsciously). Overcoming resistance requires fully understanding the many underlying factors leading to the protective behaviour that is enacted (Block, 2011; Thomas & Hardy, 2010; Yukl, 2010).

Yukl (2010) identified lack of trust, fear, and a belief that change is not achievable or is unnecessary as a few of the underlying factors of resistance. Human emotions such as self-confidence, perceived threat to personal values, and reminders of negative past experiences trigger reactions of resistance at an individual level, which can be further compounded by system dynamics at the organizational level (Yukl, 2010, pp. 300–301). Bolman and Deal (2008) also suggested that any significant change in organization has the potential to trigger conflicting symbolic responses. The first response is often to remain fixed and continue with a focus on the past, while the second is to ignore the loss entirely and embrace the future (Bolman & Deal, 2008, p. 390).

The majority of literature reviewed depicted resistance as problem that can have a negative effect on organizational change (Block, 2010; Yukl, 2010); however, Thomas and Hardy (2011) contrasted this belief by noting resistance may open the door to dialogue if it “is celebrated as a core element of effective change, then the role of change agents is to harness it, in designing and implementing successful change initiatives” (p. 324). Thomas and Hardy identified and examined two predominantly differing approaches in conceptualizing resistance: celebrating and demonizing. Through the approach of celebrating resistance, Thomas and Hardy

recognized an increase in flexible interventions that are both adversarial and facilitative; conversely, by demonizing resistance, a power imbalance is created, leading to camps of for or against within the organization (p. 329). By celebrating resistance, differing opinions, viewpoints, and ideas can be openly discussed opening the door for innovative means of achieving success in change.

### **Chapter Summary**

In this chapter I reviewed the academic literature to increase the understanding of the research inquiry and associated factors. I explored the provision of health and HIV/AIDS services within rural communities and exposed the socioeconomic realities faced by PHAs who reside within the rural regions, along with challenges of providing programming within rural regions. I further reviewed potential approaches to sustainable programming and determined there exist a number of successful collaborative actions, which can be undertaken, as well as identified challenges affecting these collaborations. The literature outlined that whole systems change efforts require a clear map of the system, inclusive of leadership at all levels within the system. The literature further identified the need to ensure and create organizational readiness for change. Finally, in this chapter I explored how leaders can help overcome resistance to change by fully understanding resistance.

In the next chapter I provide a description of the methods used to conduct the research for this inquiry. I will also explain the tools utilized and the ethical considerations for this research.

### **CHAPTER THREE: INQUIRY APPROACH AND METHODOLOGY**

In this chapter I review the approach taken for the inquiry, explain the data collection tools utilized, and describe the participants. I also included an outline of the ethical considerations undertaken to ensure the respect and safety of all participants.

#### **Inquiry Approach**

This inquiry asked the question: How can HIV North Society use collaborative strategies to increase and sustain the delivery of programming in Northern Alberta? I approached this question through the use of action research. Action research seeks to understand and find solutions to problems in a participatory fashion with those who are invested in the issue. Through the cyclical process of look, think, and act researchers and stakeholders explore the inquiry question, reflect, and then analyze, plan, and implement (Checkland & Holwell, 2007; Coghlan & Brannick, 2010; Stringer, 2007). The cyclical process then continues with *looking again* (i.e., evaluation) and planning for new action.

This methodology of action research resonated with the philosophy of HIV North and the desire to have the meaningful involvement of stakeholders, inclusive of PHAs, at all levels of program planning. Action research “seeks to engage ‘subjects’ as equal and full participants in the research process” (Stringer, 2007, p. 10). Through this inclusionary process, together with stakeholders identified above, I endeavoured to create an environment that could systematically generate new ideas and solutions relating to inquiry questions.

Action research is associated with the interpretivist paradigm, which sees the world as complex, interconnected, and ever changing. The interpretivist approach to research is one in which the researcher has personal involvement in and understanding of the research question

(Glesne, 2011). An interpretivist assumption is that participants' understandings and views are formed by their personal backgrounds and their social interactions with others. This bottom-up form of research moves from an individual's perspective to identifying patterns, and then to theory (Creswell & Plano Clark, 2007, p. 22). This is consistent with Coghlan and Brannick's (2010) discourse on experiential learning through action research, which provides one with practical knowing "the knowing that shapes the quality of your moment-to-moment action" (p. 36). This practical knowing allows stakeholders to determine what is needed to change in order to take action, which was the basis of this research.

In this action research project, I utilized a mixed-methods approach of two sequential strategies of inquiry. Creswell (2003) described this as "sequential explanatory strategy" (p. 213), whereby researchers collect and analyze quantitative data and then use this data to inform the collection and analysis of qualitative data. The value of using a mixed-method approach is that it allows the researcher to use more tools in the collection of information, without limitation (Creswell & Plano Clark, 2007). Both quantitative and qualitative data were gathered in this research and are further discussed in the Inquiry Methods section of this chapter.

### **Participants**

Stringer (2007) noted the need to have all stakeholders' participation in exploration of the issue being discussed. Stringer further identified the impossibility of having all members actively involved all of the time (p. 44). Identification of key people (i.e., persons in positions of influence) was required early in the research to ensure participation and investment in the inquiry process. Participants in this research included 41 online survey participants (of whom three self-identified as a PHA) and five participants for the conversation café. These five participants

consisted of one funder, one board member, one health care provider, one Aboriginal service provider, and one community member.

In the initial phase of this project, I invited community members consisting of social service agency providers, health care providers, funders, municipal government, Royal Canadian Mounted Police officers, and PHAs who reside within the geographical region that HIV North serves to take part in an electronic survey that was accessible from two links on the HIV North website. The two distinct links allowed for individuals to self-identify as a PHA should they so desire. The survey was anonymous, with an option upon completing the last question to access another separate link in which participants could disclose contact information should they wish to further participate in the conversation café. I sent these invitations electronically over interagency email (see Appendix B). Originally I had intended to forward invitations to PHAs who reside within HIV North's region through the Northern Alberta HIV Clinic. The inclusion of PHAs for this research was in alignment with HIV North's organizational protocols and the principles of Greater Involvement of PHAs and Meaningful Involvement of PHAs. In addition, PHAs often express a desire to be included in decisions regarding services. However, after two ethical reviews approving of this methodology and approval of recruitment through the online survey, Alberta Health Services denied the request to forward the survey directly through the Northern Alberta HIV Clinic. The online survey links were nevertheless posted on the HIV North website, which allowed participation from all individuals who access our website. This selection provided me with a snapshot understanding of the current state, needs, and further potential opportunities for collaboration within our region and also assisted in the refinement of focus questions for the conversation café.

Participants for the conversation café were to be a predetermined purposeful sample of the survey respondents who expressed an interest in attending. Given the number of individuals who came forward to attend the conversation café was only six, all were afforded the opportunity to attend, and were independently contacted and invited by the member of my advisory committee (see the Inquiry Methods section of this chapter; see also Appendix C for the conversation café invitation). Of these six participants only five attended the conversation café. As stated earlier, the conversation café included representation from funders, board members, service providers, and community members. I provide further reflection on the timing of the conversation café in the Study Conduct section in this chapter.

I recruited participants for the survey through formal invitation by email, explaining the purpose of the research, the method used in the research, and the processes for knowledge transfer and dissemination of the research findings. The first page of the survey requested that participants provide consent prior to participation and, as such, informed them about the nature of free and informed consent, as well as their right to withdraw from the research at any time (see Appendix D).

My position within the sponsoring organization placed me as an insider researcher, with a unique perspective and knowledge of the culture and structures within the organization (Coghlan & Brannick, 2010). As the Executive Director, I am in a position of influence over the front-line team. For the purposes of this research, the front-line team was excluded to mitigate any undue influence or coercion, but will be included in decisions and discussions following the completion of the research, during the implementation phase of recommendations. In addition, although PHAs could be perceived as a vulnerable population, as per our organizational protocols, PHAs

must be involved in this study based on the ethics of doing work within the principles of the Greater Involvement of PHA. Due to my experiences working with HIV North, I had anticipated that PHAs would welcome the opportunity to provide input into possibilities for collaboration and the direction of the organization.

The inquiry research team included a member of my student cohort and my editor, both of whom had no vested interest (or conflict of interest) in the outcome of my research, but was able to provide support. All members of the research team were required to complete a letter of agreement outlining responsibilities, expectations, and confidentiality (see Appendix E).

### **Inquiry Methods**

Having outlined the action research methodology and the participants involved in this inquiry, in this section I outline the way in which I implemented the methodology and engaged the participants on the ground. This section includes descriptions of the data collection tools, study conduct, and data analysis.

#### **Data collection tools**

Quantitative data were gathered through the use of online surveys to determine demographic information of the communities within HIV North's region (see Appendix F for survey questions). I sought to glean information on pre-existing collaborative strategies and develop an understanding of collaboration from as many people within the region as possible. The survey allowed for the integration of the information gained into the qualitative process in the form of new questions.

The qualitative approach was conducted in the form of a conversation café, which allowed for a more detailed exploration of the inquiry (see Appendix G). The conversation café

brought stakeholders together to engage and share ideas towards answering the inquiry question and subquestions (Brown & Isaacs, 2005; Creswell, 2003). The conversation café method was chosen as it allowed for the generation of ideas in a brief time period. I explain both of these methods in more depth below.

The first sequence of inquiry was an online survey in order to canvass a broad segment of the population within the HIV North region. The anonymous survey provided demographic location information, which was important because this study was conducted across a vast, rural region. It further served as an opportunity to receive initial input on the hypothesis that collaborative strategies could increase and sustain programming. The online survey was the preferred method as it is relatively inexpensive and allowed for rapid turnaround of data (Creswell, 2003; Vanderstoep & Johnston, 2009). I chose to use FluidSurveys (n.d.) as the online survey platform because it is a Canadian service and not subject to the United States Patriot Act (2001). I also utilized the survey to further determine potential participants for the second crucial phase of the research, the conversation café. Questions for the survey are provided in Appendix F. I distributed the invitation to participate in the survey electronically through interagency emails within HIV North's northern region and on the HIV North website (see Appendix B).

For the second phase of the inquiry I employed a method called the conversation café, also known as a world café, which allowed for the participatory inclusion of stakeholders in decisions to create change. Brown and Isaacs (2005) described the conversation café process as a unique way of bringing diverse groups together to explore through conversations and relevant questions. Brown and Isaacs explained the conversation café is effective for exploring new possibilities for action through using the collective insight of the participants in the room to



“cross-pollinate and connect diverse perspectives” (p. 40). This cross-pollinating occurs during rounds of concurrent conversations. In the conversation café, participants are divided into groups of four to five people and presented with questions that stimulate conversations. At the end of a specified time, participants are encouraged to move to different table and share with new participants what they have gleaned from the first table and question. This enables participants to link ideas and emerging thoughts together as they enter into discovery. The conversation café was determined to be an opportune venue to allow for the principle referred to in this sector as the Meaningful Involvement of PHAs. This is in line with the principles of participation in action research and is also the philosophy of HIV North, as I described earlier. This founding principle allows for the direct contribution and participation of PHAs in the planning of HIV programs and services and is fundamental to reducing stigma and discrimination associated with HIV (Canada Public Health Association, 2005, p. 16). Questions for the Conversation Café are provided in Appendix G.

### **Study conduct**

The research project began with development of an online survey, which was accessed via two distinct links on the HIV North webpage, following ethical review and approval from Royal Roads University and the University of Alberta (for Alberta Health Services). The survey consisted of open- and closed-ended questions (see Appendix F). I utilized the FluidSurveys (n.d.) platform to conduct the survey and analyze the results. One of my family members, my inquiry team member, and I pilot tested the survey process to ensure accessibility and ease of use. Following the successful pilot tests, I sent the invitation to access the online survey links via interagency emails throughout the region and also placed on the HIV North website (see

Appendix B). This was done to ensure anonymity and avoid unintended disclosure of HIV status. The survey remained active and open for a period of 2 weeks with clearly defined start and end dates and times. At the end of this period, the survey was closed to any further submissions. All relevant data obtained from the website were compiled and reviewed to determine further development of questions and to identify potential participants for the conversation café. The data obtained, including electronic and paper copies, were securely stored on a password-protected USB flash drive in a locked cabinet in my home office.

Conversation cafés are designed for use when the selected group is larger than 12 members and there is a desire to have each participant contribute to the discussion (Brown & Isaacs, 2005). Preceding the conversation café, I developed sample criteria for determining participants to ensure representation from all stakeholders. I included individuals from as many different demographics and regions as possible. I embedded instructions on how to become a candidate for participation in the conversation café in the letter of invitation, which was accessed through a link in the last question of the survey that asked whether or not participants would like to participate in a conversation café (see Appendix C). Given the short-time frame for the research to be completed, I also posted the invitation letter to participate on the HIV North website and forwarded it to a select representation from funders, community service providers, PHAs, HIV North Board, and individuals residing within the northern region via a second email.

The six individuals who responded positively to the invitation communicated directly with the advisory team member, at which time the advisory team member sent the respondent further instructions. The selection was intended to be a purposive sample that would include representation across the sector in order to encourage and stimulate dialogue across the system,

yet it was not intended to be a representative sample of all stakeholders in HIV North's programming region. I planned to limit the conversation café to 30 participants in order to mitigate undue expenditures for the sponsor agency, as HIV North was prepared to provide a travel honorarium of \$100.00 for persons travelling to attend the conversation café from the outlying regions to acknowledge the costs associated with their participation. While I cannot possibly ascertain why only six people agreed to participate in the conversation café, I recognize a number of factors may have contributed to this reality. One factor was that my request for operational administrative approval to send invitations directly to PHAs through the Northern Alberta HIV Clinic was denied despite having received two ethics approvals. This eliminated from the research a large segment of the population I had intended to reach. Due to the limited timeframe of this study, I needed to move ahead with the conversation café regardless of numbers of participants. Under different circumstances I would have delayed the process in order to recruit a larger sample of the population; however, given that my study had been delayed already by several months due to the unanticipated time required for the extra ethical reviews, I moved forward with those who expressed interest in and had committed to the study.

At the conversation café, I provided a complementary light snack and refreshments for participants. All participants signed an informed consent form prior to taking part in the conversation café (see Appendix H). I secured a suitable venue to host the event, and audio recorders, flip charts, and a camera were utilized to assist with the capture of themes and outcomes arising during the conversation café. As the researcher, I hosted the event and took pictures of the venue and the completed flip charts, while participants operated the audio recorders at each table. I did not photograph individual people.

The room was set up with four tables arranged to accommodate four participants each; however, only two tables were utilized given the smaller than anticipated number of participants. One table had three participants and the other had two participants. Each table selected one person to assist in the recording of data on the flip charts. The participants randomly self-selected the table host and rotated between the tables in five rounds of concurrent conversations discussing the preidentified open-ended questions (see Appendix G). Data captured on the flip charts during this 2.5-hour process were reviewed at the end of the conversation café and all participants member checked the data to ensure that all ideas had been accurately captured in an effort to maintain accuracy of data. To determine whether or not PHAs were in attendance, without exposing their status, I placed two decorative tins in the kitchen area with a predetermined amount of loose coins placed inside each. One box was labelled with a plus (+) sign and one labelled with a minus (–) sign. Each participant was provided with a penny and sent into the kitchen area one at a time to place the coin into the box of their choice. At the end of the conversation café in the privacy of my office I opened the tins and determined that no persons at the conversation café self-disclosed as a PHA.

### **Data analysis**

The credibility of research is based highly on the reliability of research data gathered. A criterion for validity of action research is grounded on member checks, which are designed to confirm that researchers have rigorously established the truthfulness of the data and early stages of analysis. Validity can be further demonstrated through use of multiple sources of data (Creswell & Plano Clark, 2007; Stringer, 2007). The multiple sources included electronic data from surveys, data recorded on flip charts, and transcripts of the audio recordings from

conversation café. Further perspectives were gleaned from the diverse individuals who participated in both methods. Member checks were performed multiple times during the conversation café to ascertain reliability of the data and to ensure information was correctly captured on the flip charts. Further member checking was completed via email with all participants of the conversation café when flip chart data were transposed to a Microsoft Word document and forwarded to the participants ensure the comments accurately reflected the responses of the participants. During this stage of member checking, the participants were further asked to identify their top three responses to each question and this information was correlated with the data.

Quantitative data from the surveys were recorded in a table with numerical percentages describing the consistency of the answers to the closed-ended questions. The FluidSurveys (n.d.) platform also allowed me to search the qualitative open-ended questions through identification of keywords using word clouds and then theme data online to produce bar graphs.

The qualitative data analysis for data obtained during the conversation café required the gathering and sorting of information in order to identify key themes, concepts, anomalies, and exceptions and to bring order and understanding to the data. In the first step, I familiarized myself with the data by reading, reviewing, or pawing the data multiple times (Taylor-Powell, & Renner, 2003; Ryan, & Bernard, 2003). I then collated and coded the data by organizing information into colour- and numerically-coded lists of comments to allow me to easily search for information on Microsoft Excel spreadsheets. Organizing the data in this way allowed me to pull out themes from repeated ideas, keywords, or phrases as they emerged. During this phase I found it crucial to demonstrate reflexivity by identifying my personal bias to the information

gathered and monitoring how these biases might be affecting my interpretation. By being fully transparent and understanding of the limitations of the research and describing this during the reporting of the analysis in Chapter 4, I further demonstrated trustworthiness of the data (Creswell & Miller, 2000; Glesne, 2011; Stringer, 2007).

### **Ethical Issues**

The *Tri-Council Policy Statement's* (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada [TCPS], 2010) underlying value of respect for human dignity when research involving humans is conducted is expressed in three identified core principles of respect for persons, concern for welfare, and justice (p. 8). Involving PHAs in this study adhered to these principles of respect, welfare, and justice.

In order to adhere to Royal Roads University's requirements to uphold the *Tri-Council Policy Statement* (TCPS, 2010) values, my research underwent application for ethical review with the Royal Roads University (2011) Research Ethics Board. In addition, the study proposal underwent an ethics review with both the Alberta Health Services Ethics Review Board through the University of Alberta and the Northern Alberta Clinical Research Trials Operational Approval Review. Throughout the research I was mindful that "ethical considerations are inseparable from your everyday interactions with research participants and with your data" (Glesne, 2011, p. 162).

All participants were treated with the utmost respect and in a nonjudgmental manner. All participants had the right to make a free and informed decision of whether or not they participated in any or all parts of the research. Participants' consent was documented in the form

of a signed agreement for the conversation café and included in the preamble of the survey (see Appendices D and H). Due to the nature of the anonymous survey and the collective nature of the conversation café, all results of the research will remain confidential and will not be linked with any individual at any time. For participants taking part in the second phase of conversation café, anonymity of attendance could not be guaranteed due to the group nature of the method; however, this was clearly outlined in the consent to participate.

I placed two links to the survey on the website, which both led to separate but identical surveys. One of the surveys was clearly marked for PHAs to access should they choose to self-identify as a PHA. This enabled me to confirm whether or not PHAs had participated in the survey. The other survey was open to all participants. This process allowed for the freedom of choice and maintained anonymity of participants.

During this research, I did not include any members of my front-line team due to the power-over position this presents. As described above, my position within the organization as Executive Director may have put me in a perceived power-over position with PHAs; however, excluding them from the research would have been contrary to Article 4.1 of the *Tri Council Policy Statement*: “researchers shall not exclude individuals from the opportunity to participate in research on the basis of attributes” (TCPS, 2010 p. 48). By virtue of the programming HIV North currently offers, some of the intended participants, particularly PHAs, may already have had an existing relationship with me or with my sponsor agency. Nevertheless, their voices were understood as relevant to the research, as they may have limited access to HIV North services due to where they reside. Understanding the limitations PHAs may face is crucial to the future direction of this organization. Participants were reminded that their right to access services or

treatment at any agency would not have been affected by their participation or lack of participation in this research. In addition, I ensured transparency of any potential for conflict of interest in the consent for participation documents (see Appendices D and H). For the purposes of this research, I further explained that I was acting in the role of student learner and not in my official capacity as Executive Director, although I recognize, of course, that people are whole and it is difficult to separate different roles, especially in the eyes of others.

In order to mitigate any possibility of undue harm resulting from these situations, as described earlier, a third-party inquiry team member with no connection to participants or vested interest in the study was responsible for selecting the participants for the conversation café based on criteria framework developed by the inquiry team. These precautions proved to be excessive for this study due to the low number of participants; however, there was benefit to keeping these measures in place should any follow-up work of this nature continue with HIV North.

### **Chapter Summary**

In this chapter I provided the reader with an understanding of both the theoretical underpinning and practical approach to this study. I reviewed the action research methodology that was informed by both the interpretivist paradigm and a mixed-methods approach. I described the participants and how I engaged the participants through the two methods of a survey and a conversation café. I also described how I attended to ethical concerns of respect, welfare, and justice. Finally, I hinted at some of the challenges I experienced through the ethical review and data collection stages; I will provide further reflection on these challenges in the chapters to come. With this understanding of my inquiry approach and methodology firmly in place, I turn now to a discussion of the findings and conclusions that this inquiry has produced.



## **CHAPTER FOUR: FINDINGS AND DISCUSSION**

This inquiry explored the question: How can HIV North Society use collaborative strategies to increase and sustain the delivery of programming within Northern Alberta? The inquiry was further directed by three subquestions:

1. What collaborations currently exist?
2. What could HIV North do to increase collaboration and achieve outcomes?
3. What collaborative opportunities are already available to act upon?

This chapter focuses on the findings of the inquiry, including demographic survey data, and the themes that surfaced as findings through the analysis of the data from the online survey and the conversation café. This chapter includes both a review of the six study findings and a review of the five conclusions derived from these findings. I close the chapter with a discussion of the scope and limitations of the research.

### **Study Findings**

The findings of this research are results of the analysis of both quantitative and qualitative data emerging from the online survey and the conversation café. Upon review of a compilation of this data, the following six themes were identified: (a) partnerships and collaboration, (b) community-capacity building, (c) common vision and goals, (d) communication, (e) funding, and (f) education.

I discuss each of these themes comprehensively, and each is supported by coded participant quotations from the conversation café and online survey. For the purpose of maintaining the anonymity of participants the following coding are utilized: transcripts from conversation café participants are coded P1 through to P5, data from flip charts are coded T1 and

T2, and survey participant data are coded S1 through to S41. Please note that when a comment appeared in both the conversation café transcripts and on the flip charts both identifying codes have been cited.

### **Survey data**

I have included in this section of the chapter the quantitative data collected through the online survey. Although I recognize the survey size was not statistically significant, I present the data to provide the reader a basis of understanding to support my findings. The quantitative data provide further context to the qualitative findings examined below.

As outlined in the previous chapter, data were collected through an online survey in order to provide demographic information useful in informing the conversation café questions and to provide an understanding of identified needs and opportunities for collaborations within the Northern Alberta region. The online survey was available for a 2-week period, commencing on January 8, 2013, and closing on January 22, 2013. A total of 59 responses were collected, of which 41 were complete, providing an overall completion rate of 69%. Three of the respondents self-identified as a PHA through their choice to access the specific survey link for PHAs.

Of the respondents, 63% were from Grande Prairie, with the remaining responses from Fort McMurray, Peace River/Grimshaw, Edmonton, and Grande Cache. The survey was expected to take no more than 20 minutes and the average completion was less than 9 minutes.

Participants of the survey were asked to determine if they felt there was a need for programming from HIV North within their community, and if yes, what type of programming and how frequently should it be provided. A total of 91% of participants responded yes. PHAs identified a need for support and or outreach, while the need for prevention (safer sex supplies)

programming was identified overwhelmingly by 90% of the rest of the respondents, followed by education and awareness and support for person living with HIV/AIDS or Hepatitis C. When asked how often they wanted to see this programming in their community, PHAs responded with a need for monthly programming and 56% of the rest of the respondents desired daily programming. Of interest in these findings was the fact that none of the PHAs identified a need for prevention programming in their communities.

Question 5 of the survey asked: What type of programming or service delivery do you think will have the greatest impact on preventing the spread of HIV in your Community? Participants’ responses to this question are presented in Figure 4.

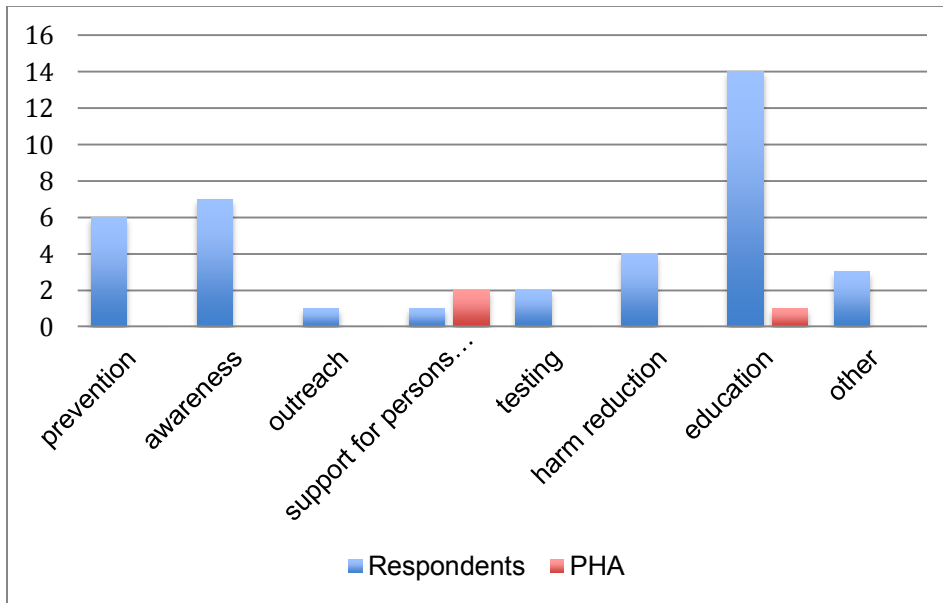


Figure 4. Participant responses indicating programs that have the greatest impact on preventing the spread of HIV in a community.

Note. PHA = Respondents who self-identified as living with HIV/AIDS; Respondents = All other respondents who completed the survey.

Another significant difference in responses was observed with Question 5, as the PHAs responded with 67% stating support for PHAs or people living with Hepatitis C, and 33%

Education, while 36% of the rest of the survey respondents gave Education as their highest result and only 3% to support for PHAs or people living with Hepatitis C.

Table 1

*Where Participants Currently Access Information and Services*

Information Access Point	Respondents	PHA
Internet or website	13	2
HIV North Society	22	1
Public Health	3	

*Note.* PHA = Persons living with HIV/AIDS.

Table 1 shows a breakdown of how respondents access information or services. Although statistically insignificant, the data led me to reflect on the difference between PHA and other respondents in how they choose to access services, and possibly requires further research to determine if this is because of the geographical area within which they reside or the lack of service access. The data, as noted in the previous section, were used to help inform the conversation café questions and were further taken into account in the analysis and representation of findings. This was done by taking the qualitative data from the open-ended questions of the survey and correlating these with the data from the conversation café. From this analysis I was able to determine six findings, which I listed at the beginning of the Study Findings section, each of which are explored in the following subsections.

### **Finding 1: Partnerships and collaborations**

While there is no consensus on what partnership and collaboration means, the research findings suggest that they are nevertheless important. The various comments from all participants in the research suggested that definitions of collaboration are diverse and personal.

From complex definitions to more succinct definitions. S23 provided the following complex definition:

Collaboration to me, means seeing where your mission and values as an organization meets with that of other organizations in your community and working together on these common issues and areas that impact upon your clients lives, working where and with whom you strategically can to address the social determinants of health that impact clients increased vulnerability to infection.

Whereas other participants provided more succinct definitions: “Working together for the best of the people in our community” (S35), and “That’s what collaboration is all about, supporting one another” (P1).

Throughout the research, participants utilized the terms partnerships and collaboration interchangeably and further defined these terms as “working together” (S27, S28, S29, P4, T1) and “sharing the load” (S27, S28, S29, P4, T1). Often times participants, when speaking of collaboration, or partnerships, added an explanation in the form of an outcome such as “to expand services” (S39), “to create awareness and prevention” (S31), or “for funding” (P1, T1, T2). Survey respondents also stated collaboration was “very important” (S16) and that it provided a “confidence someone knows how to help individuals who need it” (S21).

Collaboration was seen as a connection between service providers, stakeholders, or agencies. The metaphors “link between” (S9) or “linking with” (S38) implied a union or a bond is developed in collaborations. The commonality in the responses further implied collaboration leads to “increases in services” (S8) or “increased access to services” (S14), which was beneficial for those seeking services, as one survey respondent noted, “All services are seamless to patient” (S7). Participants of the conversation café indicated that collaboration allowed for a “stronger base” (P1) and a “sharing of best practices” (T2). The term “capitalizing on

partnerships” (P4, T2) also emerged in discussions of determining collaborative actions, which denotes a sense of direct benefit from collaboration.

Collaboration was classified as being either informal collaborations, in which everyone “sat down together and said this is what I can contribute” (P1), to being more formalized with “memorandums of understanding” (P4) or “MOUs” (P4) being developed. At table discussions during the conversation café, the emphasis of formalizing collaboration through such agreements as MOUs was to ensure “buy in” (T1, T2, P4). Participants noted that this community buy-in was necessary for successful collaborations and sustainability (P4).

Conversation café participants identified a sense of “proprietorship” (P1) as deterrent to true collaboration. The conversation café participants also noted partners may want to “guard their portion” (P1) or “protect certain areas” (P1). Three participants offered “turf protection” (P1, P3, P5) as another term for this sense of proprietorship. One survey respondent stated, “There are few true collaborations, which look at common outcomes and shared resources/programming; there are more opportunities for communication of information, which are not true collaboration” (S10). In another comment that further exemplified turf, S36 stated there appeared to be a “silo between agencies” (S36). This comment was represented in the overall survey responses, which revealed 28% of respondents did not know what collaborations if any existed in their communities, and 31% stated they were “not sure” what further opportunities for collaboration existed. Although many definitions and examples exist for collaboration, or the lack thereof, the data suggested collaboration remains multifaceted and is generally considered to produce positive outcomes.

## **Finding 2: Community capacity building**

Participants in the conversation café identified increasing community capacity as a strategy to increase and sustain programming. Participants identified two methods that may build the capacity of communities: identifying champions and peer support. The first method noted was to seek out “champions” (P3) within communities who could increase the presence and understanding of programming within smaller, more remote communities. Rather than going into a community and “delivering programming” (P1), work to “train . . . [and] build capacity locally” (P3). In building local leadership and utilizing “people who are experts in certain areas” (P1, P3) services can be provided in more communities collaboratively at a decreased cost. This collaboration was seen as a way of covering a large region without having staff in every small community and was further identified in the following survey response to question seven, which asked participants: What does collaboration in HIV programming and service delivery mean to you? One survey participant responded, “Working with other stakeholders ie; council members, police, health care practitioners and mental health collaboratively to expand services and know what the others are doing” (S39).

The second method of capacity building that participants defined was the use of “peer support” (P3) and “peer-based programming” (P3). One participant provided an example of peers, such as former drug users, who can provide outreach to other drug users, as they are “able to relate” (P3). In summary, participants determined that building the capacity of community through the use of champions and or peers to be viable methods to increasing sustainable programming.

**Finding 3: Common vision, goals, and values**

When asked what it would take to create change in delivering HIV programming in Northern Alberta, respondents noted that a common vision, goals, and values were necessary for collaboration to create change. Participants commented that, “first of all, everybody needs to be on the same page, or they should have some idea of where they would like to go” (P1). This “clarity of vision” (P1) was also seen as providing “very clear parameters around the change” (T1).

During the conversation café, participants suggested that a regional “HIV/AIDS strategy” (T1, P1, P4) could be a method utilized to determine common goals and vision. The strategy could be developed with board members and community members jointly and would be inclusive of a short- and long-term action plan (T1, P1, P4). The participants established the strategy could be built with community consultation from the existing Alberta strategy (Alberta Health and Wellness, 2011). One online survey respondent also identified that a regional HIV/AIDS strategy would provide an opportunity for joint planning and collaboration (S30). Participants discussed differing values or philosophies of potential community partners and collaborators along with the need to “ensure those philosophies are being honoured” (P5) while still supporting “good collaborative partnerships” (P5).

Conversation café participants also identified that leadership was required to lead the vision along with community-level leaders to assist with the change (P1, P3). Participants described these community leaders as “champions” (P1, P3, T1). In conclusion, leadership, a clear vision, and common goals and values are necessary to enact change.



#### **Finding 4: Communication**

Throughout the data set, the concept of collaboration was linked repeatedly to communication. Survey participants were asked the question: What opportunities for collaboration exist? One survey respondent replied, “Many, it is a matter of conversation” (S30). Two respondents identified communication as a method to increase information sharing: “share resources” (S1) and “build collaboration” (S23). From an outcome viewpoint, participants saw communication “with other agencies/disciplines” (S2) as a method to aid PHAs as well as assist with prevention initiatives.

Conversation café participants determined a need to increase communication between organizations and funders as a means to support each other moving forward. One table discussion, and one participant in particular, suggested “town halls” (T1, P1) as a good way to increase communication. Participants further determined communication was needed to identify the need within the communities for increased programming or services. Conversation café participants identified overall communication as being key to develop, maintain, and sustain collaborations.

Communication was often further described as being fully “transparent . . . accountable” (P1); that is, allowing for honest evaluations of how the collaboration is going and the ability to “receive feedback” (P1, T1). Participants provided many methods of sharing communications, such as emails, website notifications, town halls, and phone calls. Collaborations require the understanding of events and staffing. The sharing of communication was described as a way to ensure “continuity” (P2) of community, organizational, programmatic knowledge.

Conversation café participants described the building of relationships with many individuals accessing services as taking “six months to a year before you can tell they are trusting you” (P2). Within collaborative partnerships and client services, communication requires each member to have mutually respectful, culturally appropriate conversations.

### **Finding 5: Funding**

Conversation café participants identified funding as a requirement to create change and to increase and sustain programming. Participants saw funding deficits to be a reason for “turnover of staffing” (P1, P2, P3, P4, P5) and lack of services in smaller communities. Participants noted that, in smaller communities, local competition for “staff” (P3) between organizations was intensified when “wages of nonprofits” (P3) are lower than other employers, or other nonprofit organizations identify and access different funding pots and are, therefore, able to pay “10,000 per year more” (P1, P2, P3, P5) in salary. The respondents noted that competition and differences in wage levels occurs in many of the larger urban centres, including Fort McMurray and Grande Prairie, where larger industry such as oil and gas or health care offer significantly higher wages. Participants also noted that funding seemed to “come and go” (P1, P3) and was dependent on government changes or project funding ending. This cyclical nature of funding and the competition between agencies for staff proves challenging in maintaining consistency in staff and program delivery.

Providing programming and services to the large geographic region was also determined to require increased funding. One participant of the conversation café questioned “how to serve such a large area with limited resources” (P4). This same participant further stated, “Transportation is a huge issue here in the north” (P4), and the large geographic distance

between communities or services adds to increased travel costs. The closest HIV treatment clinic is in Edmonton, and HIV North was identified as having to “help with transportation to the clinic” (P3). In summary, the respondents identified increased costs to providing services within Northern Alberta due in part to its large geographic area.

The question asking what collaborative actions were needed to increase programming yielded two interesting results: corporate partnerships and staff sharing. Participants found funding was accessible if one was to “capitalize on corporate partnerships” (T2). Participants identified having organizations in the community, inclusive of the business community, backing the funding or “behind it financially in some ways” (P4). Participants’ responses to this same question revealed an opportunity to collaborate with staffing: “If my agency can only afford two days for a staff member and you can afford three, we could get one person full time and then you can keep people” (P3).

Funding was also seen as an area where again “turf protection” (P3) occurred. One participant described “a lot of times the tendency is to hide funding sources” (P2) and further identified limited funds and funding bodies often “fosters competition” (P3) rather than collaboration. In contrast, the participants noted an opportunity for collaboration on “joint funding applications” (P3, T1, T2) and sharing the information of funding opportunities. Participants saw these collaborations as a way to decrease “duplication of programming” (P4, P5), which often occurs when agencies seek funding dollars just because they are available, not because it is within the mission or mandate of an organization. Overall, lack of funding creates challenges for providing programming in Northern Alberta, and participants identified collaborative actions as possible solutions to address some of these challenges.

### **Finding 6: Education**

An overarching theme in the data was the need for increased education. Participants described education as an opportunity to “create awareness with the general public” (P1, P2, P3, P4, P5) and “increas[e] the profile in relation to HIV/AIDS” (P1, P2, P3, P4, P5). Education was also described as needing to be “appropriate for your audience” (P1) and “culturally sensitive” (P4).

When asked what would have the greatest impact on achieving HIV North’s vision of a world without AIDS, all participants in the conversation café chose education. In the online survey, 35% of respondents noted education would have the greatest impact on preventing the spread of HIV within their community.

Participants saw education as a cost-effective way of preventing HIV/AIDS and “decreasing stigma” (T1). Conversation café participants noted, “To prevent one case of HIV saves the health care system . . . probably hundreds and hundreds of thousand dollars” (P3, T1). “If people were aware and educated on the risky behaviours that HIV/AIDS is still an issue, that the rates haven’t gone down, then hopefully they would act more responsibly, they would make better choices” (P1). Although controversial, in that it can be perceived as overly simplistic, this comment is supported by government policy, specifically in the *Alberta Sexually Transmitted Infections and Blood Borne Pathogens Strategy and Action Plan* (Government of Alberta, 2011), which noted that there is a “false sense of security and unfounded optimism in the community . . . particularly among youth” (p. 21). The Government of Alberta (2011) further noted that increased education around risk and consequence was the number one goal in the action plan to increase prevention (p. 26).

Participants also identified that partnerships and collaborations would potentially increase with education and “you may get more funding” (P3) when HIV/AIDS is talked about openly in community and stigma and discrimination is reduced. Participants felt that if the business community were able to see HIV/AIDS as a health issue that has the potential to affect anyone, they would be more open to financially supporting programming efforts. Educating businesses is required to provide this vision of HIV/AIDS as a health issue of importance to the business community.

Participants determined the issue of HIV/AIDS and education to be lacking in the media: “I get very frustrated with the sitcoms and how they deal or don’t deal with this” (P2) and “the media portrayal of HIV/AIDS is not realistic” (P4). One participant asked, “How many times do you see advertisements on HIV/AIDS, you start to see advertisement on mental health, but do you see any advertisement about HIV/AIDS—no” (P1). This lack of education was further demonstrated when a participant that young individuals accessing sexually transmitted infections testing do not identify “HIV as a risk” (P2), yet they do understand the risks of syphilis, as there has been a “media campaign on syphilis” (P2). Participants found education to have decreased over the years, and suggested this was due to cut backs: “this is an easy area to cut back on. . . . Public health is really not doing that anymore, so it’s one of those things they can chop away at without public outcry” (P2). Yet research participants also identified cost-effective education opportunities such as social media campaigns using Twitter (2013) as an effective method to reach the younger population.

Conversation café participants offered two concluding statements: “Education is power” (T2) and “Knowledge is power” (T1). These statements are indicative of participants’ desire to increase education in all aspects of HIV/AIDS to achieve the vision of a world without AIDS.

In summary, the findings highlighted the participants’ perspectives of the opportunities and the potential challenges of collaboration. Participants further reinforced the need to utilize collaborative strategies as a means of increasing and sustaining programming.

### **Study Conclusions**

Based on the six preceding findings and a thorough analysis of the research data, I determined six conclusions to assist HIV North in achieving its goal of increasing and sustaining the delivery of programming within Northern Alberta. These conclusions are:

1. Collaboration and further collaborative opportunities exist and should be considered.
2. A clear vision, objective, and assessment are required to determine the collaborative strategies to be taken.
3. Communication, transparency, and accountability are crucial in constructing collaborative relationships.
4. Increasing the capacity of communities through collaborative action will assist in increasing and creating sustainable programming.
5. Education is the catalyst for initiating change.

### **Conclusion 1: Collaboration and further collaborative opportunities exist and should be considered**

The research participants identified multiple collaborations that currently exist in the HIV North region. These collaborations ranged from informal to formal and were often identified as a

partnership. The survey results demonstrated the many different ways HIV North currently collaborates within the region in response to the question: What kind of collaboration exists in your community? One survey participant identified the current collaboration between the college, Grande Prairie Friendship Centre, and HIV North, and further noted, “There is potential for increased collaboration with GPRC/HIV North” (S37). Another respondent described the collaboration between HIV North and Alberta Health Services (S8).

In the research, Senge et al. (2007) began and reviewed many collaborative initiatives, which were formed around the world in response to growing concerns with sustainability. Senge et al. noted a historic shift in our current environment in which nongovernmental organizations, businesses, and governments alike are facing “complex sustainability problems for which isolated efforts are inadequate” (p. 51). Senge et al.’s research further endorsed the need for cross-sector collaboration and new ways of operating to manage the challenge of sustainability.

As I described in Chapter 2, Austin (2000a) supported the need to increase collaborative relationships to be more effective in dealing with the demands of our complex society. Austin (2000a) additionally recommended that collaboration bridge the gulf between nonprofit agencies and public or for-profit agencies through cross-sector partnerships. The participants of this research further support this need for cross-sectoral partnerships.

As noted in Chapter 2, Kania and Kramer’s (2011) findings on the systems approach of collaborative action were reflected in this study’s participants’ comments and provided further support for using collaborative strategies. Kania and Kramer defined the idea of collective impact as “the commitment of a group of important actors from different sectors to a common agenda for solving a specific social problem” (p. 36). Conversation café participants described

collaborative opportunities and noted, “You need to make a plan together, with communities, people, stakeholders, all of the appropriate players” (P4). Collaborations have the ability to foster an atmosphere of learning from each other while working towards a collective approach to solve the dilemma of achieving HIV North’s vision of a world without AIDS, and this opportunity should be explored in depth.

**Conclusion 2: A clear vision, objective, and thorough assessment are required to determine the collaborative strategies to be taken**

The need to join in collaborative actions to increase and sustain program delivery has become apparent through the research, but of equal importance is the necessity to undertake an assessment of the current landscape to identify the best future direction. Conversation café participants identified this multiple times using varying terms such as “evaluate” (P1), “determine needs” (P3), and undertake more “research with the East Coast” (P5). Weisbord (2012) noted that in order to learn the whole system one must “always look downstream and upstream” (p. 310). Once this assessment is complete, a common and clear vision is required to reach the identified objective.

As I stated in Chapter 2, Austin (2000b) supported this concept when he suggested collaborations require “shared visioning” (p. 177) to ensure mission, strategies, and values are aligned. Hanleybrown et al. (2012) suggested that in order to move forward into collective impact effort, one must determine what the stakeholders want to work on, and evaluate the landscape to determine whether or not someone is already working on the issue. This opinion was also substantiated in the preceding participant statements.



In the conversation café participants identified that “if you have a vision, someone has to lead it” (P1). This was further noted by another participant who stated, “We need to talk about leadership . . . to ensure we are all on the same page” (P4). Yukl (2010) found the success of a vision depended greatly on how the vision was communicated. Yukl further established that by presenting a clearly articulated vision, leaders are able to build commitment to the vision. This contradicts this study’s findings and also the work of Linden (2002) who suggested a need to build the vision together rather than implementing a top-down approach. In moving forward with collaborative actions, all levels of collaborative leadership must clearly articulate messaging of the vision.

**Conclusion 3: Communication, transparency, and accountability are crucial in constructing collaborative relationships**

Just as in articulating a vision, communication plays a key role in constructing collaborative relationships. The research determined clear, open, reciprocal communication was required in all phases of collaboration, and with all members. In the online survey, one respondent referred to communication as being the “key to success” (S5) in collaboration. The participants also identified numerous methods by which to achieve this, including simple methods such as telephoning to more formalized methods such as “town hall” (P1, T2) sessions in which information could be shared.

Open communication was indicated in order to “tear down walls” (T2) and increase transparency, and was corroborated in the literature. As described in Chapter 2, Fulton (2012) discussed the need to develop an “atmosphere of trust” (p. 14) in order to create successful,

sustainable collaborations. Austin (2000b) and Linden (2002) inferred that collaborative leaders should model open communication, which likewise requires trust.

If HIV North is to be successful in building collaborative relationships, which will lead to trust and collaborative actions, full disclosure of the motive or purpose of the collaboration must occur. This is inclusive of disclosure and sharing of information, resources, funding, and funding opportunities. Conversation café participants noted that if funding applications were shared, there would be increased potential to collaborate or submit joint funding applications, which would be beneficial to all parties.

Senge et al. (2007) found that effective communication required respect, confidentiality, and the necessity to “listen, listen, listen” (p. 47). Senge et al. further concurred that the success of collaborations “rests on the quality of relationships” (p. 47).

As suggested in Chapter 2, Austin (2000b) discussed how collaborative partners need to remain accountable to each other by keeping their commitments. This demonstrates value on the investment of the collaboration (Austin, 2000b). By providing opportunities to openly engage in transparent conversations, HIV North can achieve accountability to collaborative partners, as well as provide learning opportunities for all.

**Conclusion 4: Increasing the capacity of communities through collaborative action will assist in increasing and creating sustainable programming**

Collaboration can increase community capacity as well as build leaders and leadership opportunities through collaborative learning. Conversation café participants noted many opportunities to increase community capacity, which included determining local “champions or leaders” (T1). Participants identified these champions as community leaders, peers, and also as

“cultural champions” (P4), providing an understanding of cultural differences within communities. Participants further noted champions could lead the collaborative action through awareness and promotion in their respective communities (T1, P3, P1).

The use of champions is supported in literature I reviewed in Chapter 2. Linden (2002) identified champions as being helpful in the initial stages of collaboration and aiding in defining the purpose of the collaboration. Linden (2002) further described that champions are “usually peers” (p. 85) and are often someone with “credibility and clout” (p. 85). The role of champions is dependent on the collaborative action opportunity.

Research participants determined that these leaders, or champions, would increase the capacity of their communities by creating awareness of the issue (P3). Participants further requested that HIV North, with the assistance of the champions, provide local “train the trainer” (P1) opportunities to service providers. This would allow for sustainability of the programming within local communities.

Linden (2002) concurred that by engaging large numbers of individuals in collaborative actions, they began to influence others through their conversations once they determined a benefit to the new collaboration. These individuals become champions or leaders themselves through their actions with their peers. In the literature review found in Chapter 2, this sentiment was reflected in Yukl’s (2010) and Kouzes and Posner’s (2007) statements, as they discussed enabling leadership and the sharing or giving away of power which strengthens everyone’s capacity.

**Conclusion 5: Education is a catalyst for initiating change**

Research participants demonstrated in their responses that, in order to move towards preventing HIV and the vision of a world without AIDS, education is seen as the primary catalyst for change. Education of all members on HIV prevention, testing, and treating was determined to increase awareness and decrease the social cost.

Conversation café participants noted education was a method necessary “to raise the profile” (P4) of HIV/AIDS, which could in turn increase the opportunities for collaboration and funding when people have a greater understanding that HIV affects everyone (P3). Participants felt that education would benefit all individual age groups and cultural demographics, and would put a “different spin” (P3) on HIV, moving it from something to be afraid of to an issue you can do something about.

Schein (2010) noted that when undertaking collaborations with organizations that come from different backgrounds or cultures, education may be required to enable the groups to enter into open dialogue and to develop trusting relationships. As noted earlier in this chapter, this was substantiated by the participants in the research.

Veinot and Harris (2011) conducted research in Canada and found residents in rural areas were less likely than urban dwellers to be knowledgeable about HIV/AIDS. Veinot and Harris further confirmed, “Rural Canadian communities are not yet fully understanding toward PHA’s who live in their midst” (p. 317). PHAs frequently deal with social ostracism and exclusion, poverty, homelessness, addictions, and lack of access to ASOs, all of which lead to further isolation. Educating communities about HIV/AIDS is perceived to have the ability to reduce the stigma and discrimination faced by PHAs. Although I recognize that education is required and

very important, on its own, this may not be adequate to enact behavioural change. As noted in Chapter 2, Guenter et al. (2005) found that ASOs have “embraced a philosophical stance that perceives HIV transmission to be a product of a complex web of social vulnerability” (p. 35). No longer focusing on education alone, ASOs focus on health promotion and on social determinants of health when tailoring their programming to seek behavioural change. Further supports would assist in encouraging this change. All of these suggestions identify relevant opportunities for future research.

### **Scope and Limitations of the Research Inquiry**

Limitations to my inquiry were primarily in relation to the representation of participants and the tight timelines that resulted from an unanticipated additional ethics reviews process required to send invitations through a third party. In this section I describe some of the challenges encountered that resulted in limitations to the research.

Although the invitations to participate were distributed through the HIV North website and interagency emails throughout the Northern Alberta region served by HIV North, representation from many of the communities was missing. The lengthy time, 3 months, required for the three ethics reviews resulted in the online survey being posted for 2 weeks in early January, at a time when potential participants may still have been away for the holiday season. This resulted in only two of the communities that are currently not provided with services by HIV North being represented in the online survey data.

As a researcher, I made a concerted effort to include the voices of PHAs in the research. As discussed earlier, the meaningful involvement of PHAs is sought at all levels of programming in the organization, including in research. Unfortunately, after two ethics approvals, and a third

application through the Northern Alberta Clinical Research Trials, operational administrative approval was denied. This approval was needed in order to have invitations mailed out from the Northern Alberta HIV Clinic to PHAs residing within the Northern region. The denial expressed a concern for maintaining the confidentiality of PHAs through a mail out of the invitations. Although this decision resulted in missing important data, namely the voices of PHAs in the research, it provided assurance to me the researcher that the institutions that provide services are protecting the status of PHAs. In future research, I will consult the Northern Alberta HIV Clinic for guidance on how best to provide PHAs with the opportunity to participate.

Due to the tight timelines, which required that I complete the data collection in order to meet the requirements of graduation, only six individuals contacted the external team member to take part in the conversation café, and only five individuals attended the session. I chose the conversation café as a method so that a large group of community members could contribute to the research. The meagre sample size made it difficult to triangulate data findings, and, ideally, I would have not have used a large group method for a sample of that size. In spite of these challenges, the conversation café provided a much needed baseline information in moving forward. The open conversations generated interest to progress, as was demonstrated by the participants' desire to increase sustainable programming to more individuals within Northern Alberta.

As mentioned in the previous chapter, only 69% of the returned surveys were completed in full. This result suggests there was a limitation in the phrasing of some of the survey questions. This was further corroborated when a participant of the conversation café commented that one of the questions was not clearly understood.

A further limitation was that the link from the survey to the invitation to take part in the conversation café proved to be a complicated process for some survey participants to follow. Survey participants were linked directly to the invitation when they answered yes to Question 10, which asked whether or not they would like to participate in the conversation café. In order to realize that one must contact the inquiry team member to be included in the selection of participants, the survey respondent would have had to read the entire three-page invitation. The survey identified 13 individuals wanting to take part in the conversation café but only six actually read the invitation to determine the need to further contact the team member, who would then select the participants.

As suggested earlier, a final constraint may have been the location of the conversation café, which was held in Grande Prairie. The invitation did not state that funding would be available to assist with travel to the event. This could have been more clearly communicated in the invitation to participate and on the website.

In spite of all these challenges, my study yielded important findings, which can be utilized as a baseline study to be expanded upon in future. Although small in number of participants, the data from the conversation café was rich in content. The unique individual perspectives of the participants provided another lens through which to view the question of how HIV North can use collaborative strategies to increase and sustain the delivery of programming within Northern Alberta.

The obstacles I faced provided me with important lessons on conducting research in future. I will ensure the appropriate method is chosen, keeping in mind the number of participants expected. I will provide clear instructions in all communications inclusive of ethics

applications, invitations, and process. Finally, I will allow time for the unexpected hurdles that are part of our day-to-day lives when determining timelines. Each of these lessons will guide my future endeavours.

### **Chapter Summary**

In this chapter I summarized the participants' responses from the online survey and conversation café. I further identified the five key themes, or findings, determined during the analysis of the data, and supported by literature. I also provided the study conclusions, which were supported by both the study's findings and literature. I closed this chapter with a discussion of the scope and limitations of the research. The upcoming chapter concludes this thesis by exploring the implications of this study, recommendations for the organization, and implications for future research.



## CHAPTER FIVE: INQUIRY IMPLICATIONS

In this chapter, I present the recommendations culminating from the study conclusions to assist in answering the research question: How can HIV North Society use collaborative strategies to increase and sustain the delivery of programming with Northern Alberta? The chapter also includes a review of the organization implications and recommendations for future research.

### Study Recommendations

After careful review and consideration of the data collected and the review of relevant literature I have made the following five recommendations for HIV North:

1. Involve the whole system of HIV North, including board members and the front-line team in reviewing the findings of this research.
2. Undertake a thorough evaluation of all current existing collaborative partnerships.
3. Further explore using Kania and Kramer's (2011) collective impact approach in HIV North's collaborative action to effect change.
4. Investigate the opportunity to host further conversation cafés within the four largest communities in the region.
5. Encourage and foster an environment of collaboration.

### **Recommendation 1: Involve the whole system of HIV North, including board members and the front-line team in reviewing the findings of this research**

Everyone's input is necessary to determine the organization's readiness to initiate a whole system change. The absence of the front-line team in this research due to ethical considerations resulted in missing data in the research. The front-line team of the organization, as

the “hands and feet” of program delivery, hold a wealth of information that should be further explored. My first recommendation, therefore, is to bring this group together to share the findings of the research and add the missing data. Similarly, it is important for HIV North board members to be involved in the early dissemination of the research findings. As the governing body of the organization, the board of directors must determine the strategic direction and task the Executive Director with implementation. Bringing the board and team members together to share their personal perspectives of the study will provide a more comprehensive understanding of a whole system change initiative and identify champions within the organization to bring this to fruition.

As Weisbord (2012) stated, “The sensible way to make a commitment to our people is to have our people work together in rethinking their work” (p. 204). By sharing this research and building upon the findings, HIV North can determine the readiness within the organization to take on further whole systems change through collaborative actions. This is crucial to the organizational transformation, as there must be a commitment by the leader and the leadership team to support the change in order for it to be successful.

Based on these findings, my first recommendations would further delineate the need to make this process of coming together a two-step process. The first step is to add missing data and determine the goal, and the second step is to review the values and beliefs of HIV North with the members of the organization and determine the alignment of both to the potential collaborative actions towards whole systems change.

**Recommendation 2: Undertake a thorough evaluation of all current existing collaborative partnerships**

Entering into collaborative partnerships has been a reality for HIV North over the years; however, effectively reviewing those partnerships has been challenging. Quinn (2004) stated, “Most of us in the organizational world are engulfed in action, at the expense of contemplation and reflection” (p. 99). I recommend stakeholders reflect and evaluate to identify what collaborative actions are, and are not, working in the existing system. This will assist in determining what principles and practices need to be adopted or left behind to achieve future success. If HIV North does not learn from the programs and collaborative actions that work and utilize them, collaboration to achieve collective impact will be unsuccessful.

The evaluation process can be supplemented by the current yearly evaluation and partnership review that is undertaken by the external evaluator. However, it is my recommendation that a more extensive evaluation be completed on all current collaborations as well as the suggested collaborations identified in the research.

Organizations are all reliant on the system as a whole for resources and support, yet they each have unique perspective, which determines the process, participants, and route they pursue, (Bolman & Deal, 2008). Understanding this system of interconnected partnerships and potential collaborative partnerships through evaluation will provide HIV North with a map and template for further collaborative action.

**Recommendation 3: Further explore using Kania and Kramer's (2011) collective impact approach in HIV North's collaborative action to effect change**

The idea of collaborating across sectors and utilizing a collective impact approach to solve a specific problem would be a new area for HIV North to explore. It is this new and innovative thinking that was recommended during the research, when a conversation café participant identified the need to “think outside of the box and be innovative” (P4). My third recommendation is to explore this collective approach in more detail to determine whether or not it is a fit within the organization as HIV North moves forward in collaborative actions.

In the academic literature I reviewed in Chapter 2, Kania and Kramer (2011) and Corcoran et al. (2012) discussed collaboration and identified collective impact as an effective way of achieving collaboration to effect large-scale social change. Increasing the understanding and use of HIV prevention methods requires large-scale change if HIV North is to realize the vision of a world without AIDS.

Typically, ASOs would identify a need or gap in services, create a service delivery program to address the need, evaluate the program to show results, and increase services to more individuals in hopes of creating change. Occasionally, this increase in services would include collaboration. Collective impact has the potential to reverse these traditional methods utilized by ASOs in social change process.

Collective impact efforts have been identified as an emerging method and have been utilized successfully in the United States as well as in Canada (Hanleybrown et al., 2012). Most recently in Alberta, the Calgary Homeless Foundation has demonstrated collective impact as it addressed the growing number of homeless within the community (Hanleybrown et al., 2012).

The literature reflected that collective impact is most successful when utilized to address “adaptive problems” (Kania & Kramer, 2011, p. 39), in which the answer is unknown or unattainable by a single entity. Addressing HIV/AIDS prevention and awareness would identify as such a social problem. I recommend further assessment of this model of collaboration for HIV North in the next 6 months. To do this I recommend HIV North begin with conversations with the leaders of the Calgary Homeless Foundation and the Vibrant Communities. Secondly I recommend that HIV North send a representative to one of the Tamarack Institute’s (n.d.) Collective Impact workshops in Canada to learn more about the model and how to lead a collective impact initiative. Thirdly, I recommend that HIV North consider in what ways Collective Impact methods could correspond with other social movements around collaborative, community-based care; for example, the Communities That Care movement (Flynn, 2008).

**Recommendation 4: Investigate the opportunity to host further conversation cafés within the four largest communities in the region**

Given the small sample size of participants in the research, I recommend exploring the opportunity to repeat the process of the conversation café in some of the communities within the Northern Alberta region. My recommendation is to seek conversations and build reciprocal relationships within four of the larger communities in the region of Northern Alberta where services are currently not being provided. This will be a first step in building local cross-system or cross-agency collaborations. These communities are Valleyview, Fox Creek, Grande Cache, and High Level.

Hosting further conversation cafés in the region would serve two purposes: One would be to bring individuals within the region together to explore collaboration and be innovative, and

the other would be to increase the awareness of HIV/AIDS through an informal educational opportunity. Taking conversations to the communities rather than asking community members to travel may increase the participation in the further exploration of the topic of collaboration.

Collaborations require successful relationships and collaborative leaders. Collaborative leaders, however, “don’t exist in isolation – they succeed by building successful relationships, and to do that they need other collaborative leaders to build relationships with” (Archer & Cameron, 2009, Chapter 11, And Finally section, para. 1). Relationships flourish when people frequently enter into opportunities to share and explore experiences and lessons learned. Pratt, Gordon, and Plamping (2005) stated, “Whole system working reveals and supports networks of connections and the communications that sustain them” (Chapter 3, “Web of Connections,” para. 3). Further, conversation cafés provide an opportunity to initiate whole systems change, as through this process HIV North will intentionally invite representatives from all the different stakeholder groups. Entering into open conversation with other communities, their leaders, or champions allows HIV North to disclose its motivation behind seeking collaborative actions. These conversations will also serve to forge new relationships as well as to build on existing networks. We have the potential through conversations to determine if there are opportunities for further joint funding applications. Conversations should include active listening, reflection, and observation on behalf of HIV North, rather than one-way communication, to maximize learning from other stakeholder groups.

**Recommendation 5: Encourage and foster an environment of collaboration**

Ralph Nader (as cited in Quinn, 2004) once said, “I start with the premise that the function of leadership is to produce more leaders not more followers” (p. 64). Research has

shown that fostering an environment of collaboration requires leaders to promote positive social relationships and encourage collaboration among all members. Leaders must walk the talk by showing through daily behaviours that collaboration is important and valued. Eventually others will emulate the actions, creating the possibility that organizational transformation can occur (Kramer & Crespy, 2011; Linden, 2002).

Encouraging a collaborative environment requires positive, supportive communication and expressing a clear vision. This communication should encourage collective leadership throughout the organization and utilize the diverse expertise of its members. As I outlined in Chapter 2, Raelin (2006) stated, “When people who have a stake in a venture are given every chance to participate in the venture, including its implementation their commitment to the venture will be assured” (p. 155). When a shared leadership approach is taken by all individuals, along with the freedom to work together and to make mistakes, a collaborative atmosphere can be attained by HIV North.

By encouraging open dialogue, shared responsibility, and planning on a regular basis with all members of HIV North, and by promoting positive social relations within the organization, HIV North will foster collaboration across organizational boundaries. As I have reviewed the recommendations from the research, in the next section, I now discuss the implications these recommendations have on the organization.

### **Organizational Implications**

This section seeks to clarify the implications to the organization from the research findings. The research provides HIV North with a number of recommendations, which I listed earlier in this chapter. These recommendations require consideration from the Board of Directors

of HIV North to determine the next steps and to assess strategic implications as the organization moves into a new funding cycle in 2014. The recommendations further require commitment to support the first steps in exploring the recommended whole system change. As discussed, I recommend the research and direction be shared with the front-line team of HIV North for inclusion in the current organizational planning and future planning for the next funding cycle. I have spoken with the organizational sponsor, who is also the Board President, and I reviewed these recommendations. This has led to further determining that the sharing of this information will occur when the thesis is completed. In May 2013, all organizational members will gather as a team for the annual general meeting; I recommend that HIV North set aside time in this day to review together the key salient points and recommendations from this research.

Evaluation efforts are currently underway within the organization, as this is currently HIV North's fiscal year end. We will utilize these evaluations to gather information on our current collaborative partnerships. This study has allowed me to direct the external evaluators to closely examine HIV North's collaborative partnerships and to gain valuable feedback from these partners.

Should the recommendations be accepted, funding to support collaborative evaluation, conversation cafés, and further exploration of collective impact process will be required. During the organizational review of this document, the project sponsor and I discussed the need for funding and discussed opportunities to utilize funding already in existence. Evaluation is already a planned expenditure for the agency, as is professional development. This funding, although limited, would allow for expansion of the evaluation on collaborative partners over the next 6



months and also allow a member of the organization to go to the training on collective impact process, which will be held in Toronto in April.

Upon researching the collective impact process I determined that many of the collective impact initiatives were able to secure funding from larger funding bodies. Proposals could be written once consensus was made by all members of the HIV North. A correlation to this whole systems change could be added to HIV North's current funding proposals, which will be submitted by fall of 2013. A review with the organizational sponsor along with the data from the survey identified four locations in which to start conversations. These locations are Grande Cache, Valleyview, Fox Creek, and High Level. The initial conversation will be via telephone in order to identify potential participants for future conversation café. These steps are expected to occur in early 2014.

Should the recommendations not be implemented, the organization is unable to further increase sustainable programming, and status quo remains. Future and existing collaborative opportunities may diminish as partnerships are not evaluated or maintained. Finally, the complex systems structure remains unaided, which leads to burn out of employees as HIV North struggles to provide services to the newly expanded region.

### **Implications for Future Inquiry**

This research project identified key areas in which to explore collaborative actions to increase and sustain the delivery of programming within the Northern Alberta region.

Conversation café participants also expressed a desire to continue with the research to provide evidence of best practices, as well as a venue from which to further collaborate. One conversation café participant noted that research “of the work to date on HIV programming by

HIV North in the North” (P4) would be relevant to the organization in determining next steps or further research opportunities. Whereas P5 suggested collaborative research with the East Coast on spread of sexually transmitted infections would be warranted given the transient workers within the HIV North region. As a result of the data collected in this research, further exploration of providing supports through online venues (internet) could assist in determining the validity of this format for program delivery to rural PHAs. As the sample size of PHAs was too small for comparison, determining a method of reaching this population with the assistance of the Northern Alberta HIV Clinic could provide new insight.

### **Chapter Summary and Closing Comments**

In this chapter I have presented the five recommendations evolving from the study conclusions. I then reviewed the organizational implications and provided a few recommendations for future inquiry. To conclude this study, below I provide a brief summary of how my initial inspiration for the study was carried through to the recommendations listed above. I close by reminding readers of how these recommendations support HIV North in moving toward our vision of a world without AIDS.

The driving factor for this research project was my desire to increase and sustain programming to many of the communities within HIV North’s large region in the face of limited funding. The research explored the complex system within which HIV North resides and provided an academic literature review on topics relevant to supply diverse HIV programming and collaborative actions. I obtained data through a mixed-methods approach; I then analyzed and compiled the data, which allowed for the determination of themes, conclusions, and

recommendations. These recommendations, I believe, will have a great impact on the delivery of programming within the north region of Alberta and future collaborations.

Ensuring all individuals have access to programming and services, regardless of whether or not they live in a large city or a rural community, is fundamentally a social obligation and right. As an organization, HIV North strives to provide these services to all individuals regardless of status, gender, race, age, socioeconomic background, or lifestyle choice. In this day and age, one new case of HIV is too many, especially as we have the knowledge of how to prevent the virus from spreading. As an individual, I, like many others, truly do believe that the vision of a world without AIDS is attainable. This vision cannot be achieved by one organization; rather, it requires a concerted effort by all. Collaboration for collective impact may very well be the key towards achieving this vision in practice.

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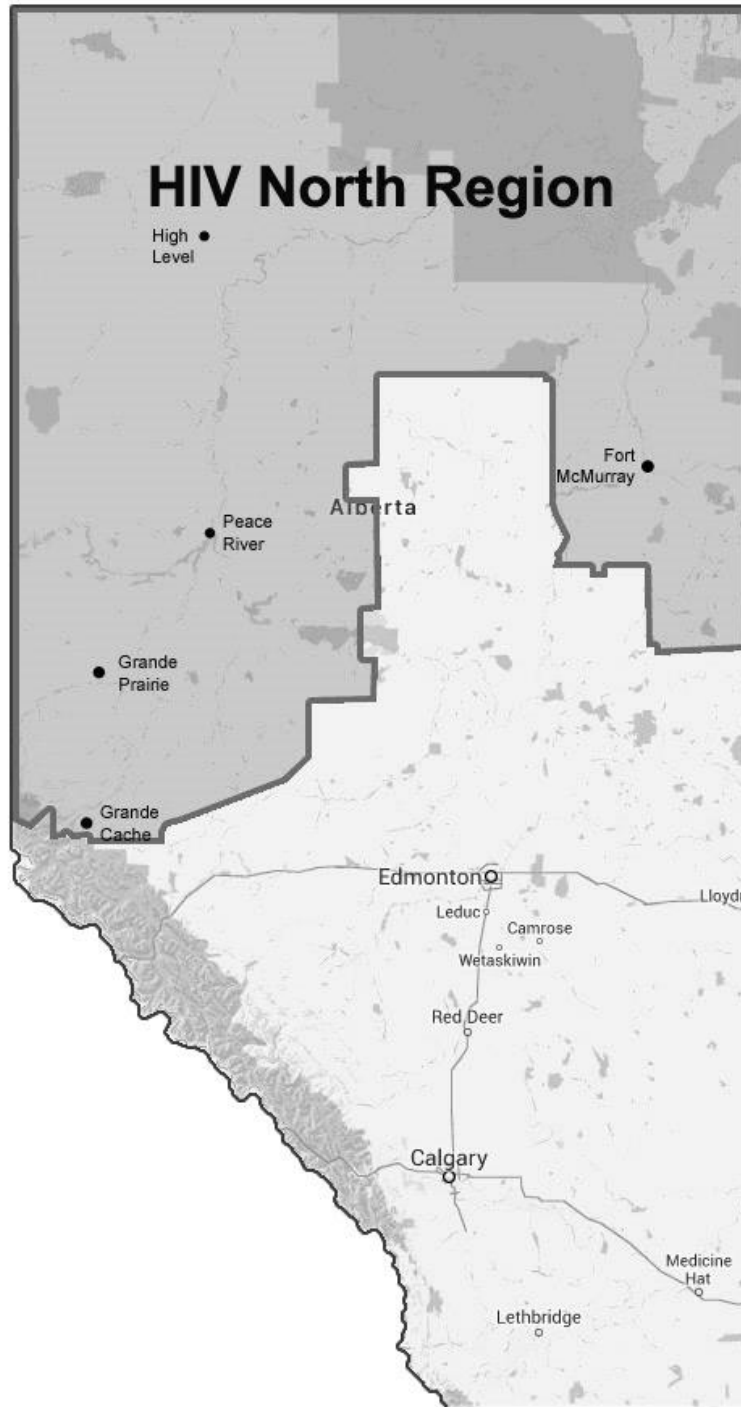
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**APPENDIX A: HIV NORTH SOCIETY REGION**



*Note. Map data © 2014 Google*

## **APPENDIX B: LETTER OF INVITATION FOR – SURVEY**

### **Exploring Increased HIV Program Delivery in Northern Alberta**

[Date]

Dear [Prospective Participant]:

I would like to invite you to be a part of a research project that I am conducting. This project is part of the requirement for a Master's Degree in Leadership, at Royal Roads University. My name is Brenda Yamkowy and my credentials with Royal Roads University can be established by calling Niels Agger-Gupta, Program Head, MA Leadership at [telephone number].

The objective of my research project is to determine how HIV North Society can use collaborative strategies to sustainably increase programming to more communities within a large region in northern Alberta. In addition to submitting my final report to Royal Roads University in partial fulfillment for a Master of Arts in Leadership Degree, I will also be sharing my research findings with HIV North Society, Alberta Health, Public Health Agency of Canada, Alberta Community Council on HIV, future publications and conferences. A final copy of this report will also be archived in the RRU Library electronically, as well as in the Thesis Canada Portal of Library and Archives Canada.

My research project will consist of an online survey and a Conversation Café. The proposed questions will explore HIV programming needs within northern Alberta, what types of collaboration already exists and what opportunities for collaboration exist to sustain increased programming.

This invitation is being extended to you to participate in the online survey. You were chosen as a prospective participant because of the northern Alberta region or community, within which you reside, and/or within which you provide services. The data gathered from this survey will serve to aid in developing the future discussion topics for the Conversation Café.

Information will be recorded electronically and where appropriate summarized, in anonymous format, in the body of the final report. At no time will any specific comments be attributed to any individual unless your specific agreement has been obtained beforehand. All documentation will be kept strictly confidential.

The data, both electronic files and paper copies will be retained and kept securely in a locked cabinet for the duration of the project. After a period of four years, all data will be destroyed.

You are at no time required to participate in this research project. If you do choose to participate, you are free to withdraw at any time without prejudice. Similarly, if you choose not to participate in this research project, this information will also be maintained in confidence.

I understand that my role as Executive Director of HIV North Society may influence your desire to participate in this study. It is important that you understand that my role during this research project is one of researcher and facilitator, and not as Executive Director of HIV North Society.

Your ability to access services will not be impacted in any way by your choice of whether or not to participate in this project.

If you would like to participate in my research project, please access the consent and survey at the attached link [survey link].

Please feel free to contact me at any time should you have additional questions regarding the project and its outcomes.

Sincerely,

Brenda Yamkowy

[email address]

[telephone number]

[telephone number]

## **APPENDIX C: LETTER OF INVITATION FOR CONVERSATION CAFÉ**

### **Exploring Increased HIV Program Delivery in Northern Alberta**

[Date]

Dear Prospective Participant

I would like to invite you to be a part of a research project that I am conducting. This project is part of the requirement for a Master's Degree in Leadership, at Royal Roads University. My name is Brenda Yamkowy and my credentials with Royal Roads University can be established by calling Niels Agger-Gupta, Program Head, MA Leadership at [telephone number].

The objective of my research project is to determine how HIV North Society can use collaborative strategies to sustainably increase programming to more communities within a large region in northern Alberta. In addition to submitting my final report to Royal Roads University in partial fulfillment for a Master of Arts in Leadership Degree, I will also be sharing my research findings with HIV North Society, Alberta Health, Public Health Agency of Canada, and Alberta Community Council on HIV, future publications and conferences. A final copy of this report will also be archived in the RRU Library electronically, as well as in the Thesis Canada Portal of Library and Archives Canada.

My research project consists of an online survey and a Conversation Café. The survey is now complete and has been used to generate questions for this next stage of the research. The questions will explore HIV programming needs within northern Alberta, what types of collaboration already exists, and what opportunities for collaboration exist to sustain increased programming.

This invitation is being extended to you to participate in the Conversation Café. You were chosen as a prospective participant because of the northern Alberta region or community, within which you reside, and/or within which you provide services, you self-identified as a participant in the first phase of the online survey, or you have provided supports for projects in the past.

The Conversation Café will take place on (insert date) at (insert time). It will take approximately three hours and will include light refreshments.

Information gathered will be recorded by audio and visual recorders throughout the Café, as well as recorded in hand written format at each table and where appropriate summarized, in anonymous format, in the body of the final report. By the very nature of Conversation Café the information gathered is not anonymous; however, all participants are asked to keep the information confidential. At no time will any specific comments be attributed to any individual unless your specific agreement has been obtained beforehand. Photographs will be taken of the flip charts, notes created by participants, and the layout of the room. No photos of you will be included in any documentation. Audio recorders will be utilized to assist with the capture of themes and outcomes arising during the Conversation Café.

All documentation will be kept strictly confidential.

The data will be retained and kept securely in a locked cabinet for the duration of the project. Upon the completion and final acceptance of the thesis report, all data will be retained for a further four years after which it will be destroyed. Any data or information pertaining to an individual who has withdrawn from the research during the Conversation Café will remain with the research project.

You are at no time required to participate in this research project. Furthermore, your current or future right to access services or treatment at any agency will not be affected by whether you participate in the research or not. If you do choose to participate, you are free to withdraw at any time without prejudice. Similarly, if you choose not to participate in this research project, this information will also be maintained in confidence. However if you choose to withdraw during the Conversation Café or following, any information given during the Café will remain with the project since your comments will be compiled with those of other participants and will therefore be impossible to separate.

HIV North Society employs me as the Executive Director; however, I am conducting this research as a Masters of Arts in Leadership student. I expressly state this to avoid any confusion regarding my role.

In addition, it is important that you understand that people from a broad cross-section of society are being invited to participate in this Conversation

Café, including funders, Health and community representatives, municipal government and RCMP. It is therefore possible you may recognize other participants and, for reasons of confidentiality, I will not be able to disclose a participant list in advance. I include this information to help you decide on whether or not to participate.

**If you would like to participate in my research project, please contact the research advisory team member Andrea Leven-Marcon by email at [email address]. This neutral member of the research advisory team, will select participants according to specific criteria. Only those persons meeting the selection criteria will be contacted to participate.** All interested parties will have access to the final report.

Please feel free to contact me at any time should you have additional questions regarding the project and its outcomes.

Sincerely,

Brenda Yamkowy

[email address]

[telephone number]

[telephone number]

## **APPENDIX D: INFORMED CONSENT – SURVEY**

### **Exploring Increase HIV Program Delivery in Northern Alberta**

My name is Brenda Yamkowy, and this research project is part of the requirement for a Masters of Arts in Leadership degree at Royal Roads University. My credentials with Royal Roads University can be established by telephoning Niels Agger-Gupta, Program Head, Masters in Leadership, Royal Roads University at [telephone number].

The objective of this research is to determine how HIV North Society can sustainably increase programming to more communities within a large region in northern Alberta. In addition to submitting my final report to Royal Roads University in partial fulfillment for a Master of Arts in Leadership Degree, I will also be sharing my research findings with HIV North Society, Alberta Health, Public Health Agency of Canada, Alberta Community Council on HIV, as well as through future publications and conferences. A final copy of this report will also be archived in the RRU Library electronically, as well as in the Thesis Canada Portal of Library and Archives Canada.

This online survey consists of eleven questions and is foreseen to take no more than twenty minutes to complete. The questions explore HIV programming within northern Alberta, where individuals access information/services currently, what types of collaboration already exists and what opportunities for collaboration exist to sustain increased programming. It will also seek to identify key outcomes HIV North should focus on. The survey may be accessed from (date) to (date). It will be closed on (date) to collect data.

Fluid Survey, a Canadian based company, is the platform used for this anonymous online survey. Information will be recorded electronically and summarized, in anonymous format, in the body of the final report. Your responses are anonymous and at no time will any specific comments from the survey be attributed to any individual. All documentation resulting from this survey will be kept strictly confidential.

The data will be retained and kept securely in a locked cabinet for the duration of the project. Upon the completion and final acceptance of the thesis report, all data will be retained for a further four years after which it will be destroyed.

HIV North Society employs me as the Executive Director; however, I am conducting this research as a Masters of Arts in Leadership student. I expressly state this to avoid any confusion regarding my role.

You are not required to participate in this research project and your choice of whether or not to participate will have no bearing on your current or future access to services at HIV North. If you do choose to participate, you are free to withdraw at any time without prejudice by closing your web browser prior to pressing submit at the end of the survey. If you have completed and submitted the survey it is impossible to remove data as it is anonymous.

The direct benefit to you participating in this research is the opportunity to have your voice, thoughts and opinions stated through the survey. You will be contributing to the potential of organizational change for HIV North Society. There are no identifiable potential risks of participating in this research.

Should you have any questions regarding your rights as a research participant, please contact the University of Alberta Research Ethics Office at [telephone number]. Collect calls will be accepted.

For further information please contact me at:

Email: [email address]

Telephone: [telephone number]

Sincerely,

Brenda Yamkowy

By accessing the following link to the survey you are declaring you are 18 years of age or older and you are giving informed consent. [Survey link]



## **APPENDIX E: INQUIRY TEAM MEMBER LETTER OF AGREEMENT**

In partial fulfillment of the requirement for a Master of Arts in Leadership Degree at Royal Roads University, *Brenda Yamkowy* (the Student) will be conducting an inquiry research study at *HIV North Society* to determine how HIV North Society can sustainably increase programming to more communities within a large region in northern Alberta. The Student's credentials with Royal Roads University can be established by calling Dr. Niels Agger-Gupta, Program Head, MA Leadership (Classic), at [telephone number].

### **Inquiry Team Member Role Description**

As a volunteer Inquiry Team Member assisting the Student with this project, your role may include one or more of the following: providing advice on the relevance and wording of questions and letters of invitation, supporting the logistics of the data-gathering methods, including observing, assisting, or facilitating a Conversation Café, taking notes, transcribing, or analyzing data, to assist the Student and the *HIV North Society* organizational change process. In the course of this activity, you may be privy to confidential inquiry data.

### **Confidentiality of Inquiry Data**

In compliance with the Royal Roads University Research Ethics Policy, under which this inquiry project is being conducted, all personal identifiers and any other confidential information generated or accessed by the inquiry team advisor will only be used in the performance of the functions of this project, and must not be disclosed to anyone other than persons authorized to receive it, both during the inquiry period and beyond it. Recorded information in all formats is covered by this agreement. Personal identifiers include participant names, contact information, personally identifying turns of phrase or comments, and any other personally identifying information.

### **Bridging Student's Potential or Actual Ethical Conflict**

In situations where potential participants in a work setting report directly to the Student, you, as a neutral third party with no supervisory relationship with either the Student or potential participants, may be asked to work closely with the Student to bridge this potential or actual conflict of interest in this study. Such requests may include asking the Inquiry Team Advisor to: send out the letter of invitation to potential participants, receive letters/emails of interest in participation from potential participants, independently make a selection of received participant requests based on criteria you and the Student will have worked out previously, formalize the logistics for the data-gather method, including contacting the participants about the time and location of the Conversation Café using the protocol and questions worked out previously with the Student, and producing written transcripts of the Conversation Café with all personal identifiers removed before the transcripts are brought back to the Student for the data analysis phase of the study.

This strategy means that potential participants with a direct relationship, and or those participants who access services from HIV North Society, will be assured they can confidentially turn down

the participation request from the Executive Director of HIV North (the Student), as this process conceals from the Student which potential participants chose not to participate or simply were not selected by you, the third party, because they were out of the selection criteria range (they might have been a participant request coming after the number of participants sought, for example, interview request number 6 when only 5 participants are sought, or focus group request number 10 when up to 9 participants would be selected for a focus group). Inquiry Team members asked to take on such 3<sup>rd</sup> party duties in this study will be under the direction of the Student and will be fully briefed by the Student as to how this process will work, including specific expectations, and the methods to be employed in conducting the elements of the inquiry with the Student's direct reports, and will be given every support possible by the Student, except where such support would reveal the identities of the actual participants.

Personal information will be collected, recorded, corrected, accessed, altered, used, disclosed, retained, secured and destroyed as directed by the Student, under direction of the Royal Roads Academic Supervisor.

Inquiry Team Members who are uncertain whether any information they may wish to share about the project they are working on is personal or confidential will verify this with Brenda Yamkowy the Student.

**Statement of Informed Consent:**

I have read and understand this agreement.

\_\_\_\_\_  
Name (Please Print)                      Signature                      Date

**APPENDIX F: SURVEY QUESTIONS**

1. In what community/town/village/city of northern Alberta do you reside and/or provide services?  
\_\_\_\_\_
  
2. Do you feel you need programming from HIV North Society in your community?  
 Yes  
 No  
 Don't know
  
3. If you answered yes to question two, what type of programming would you like to see in your community? (choose all that apply)  
 Prevention (safer sex supplies)  
 Awareness  
 Outreach  
 Support for Persons Living With HIV/AIDS, or Hepatitis C  
 Testing  
 Harm Reduction (needle distribution and recovery)  
 Education  
 Other, please specify \_\_\_\_\_
  
4. How often would you like to see this programming in your community?  
 Monthly  
 Weekly  
 Daily  
 Other, please specify \_\_\_\_\_
  
5. What type of programming or service deliver do you think will have the greatest impact on preventing the spread of HIV in your community?  
 Prevention (safer sex supplies)  
 Awareness  
 Outreach  
 Support for person living with HIV/AIDS or Hepatitis C  
 Testing  
 Harm reduction (needle distribution and recovery)  
 Education  
 Other (please specify) \_\_\_\_\_
  
6. Where do you currently access information and or services?
  
7. What does collaboration in HIV programming and service delivery mean to you?
  
8. What kind of collaboration exists in your community?

9. What opportunities for collaboration exist?

10. Would you like to participate in a Conversation Café to further explore this topic?

- Yes
- No
- submit

Thank you for participating in this survey!

**APPENDIX G: CONVERSATION CAFÉ QUESTIONS**

1. What would it take to create change in delivering HIV programming in northern Alberta?
2. What collaborative actions are needed to increase programming?
3. What possible collaborative solutions are there to sustaining programming?
4. What does collaboration mean moving forward: How can we support each other in taking next steps?
5. Which of the following do you believe would have the greatest impact on achieving HIV North Society's vision of a world without AIDS:
  - Increased HIV testing
  - Increased HIV treatment
  - Increased access to safe sex supplies
  - Increased education
  - Increased distribution of drug use supplies (needle exchange)

## **APPENDIX H: INFORMED CONSENT FOR CONVERSATION CAFÉ**

### **Exploring Increased HIV Program Delivery in Northern Alberta**

My name is Brenda Yamkowy, and this research project is part of the requirement for a Masters of Arts in Leadership degree at Royal Roads University. My credentials with Royal Roads University can be established by telephoning Niels Agger-Gupta, Program Head, Masters in Leadership, Royal Roads University at [telephone number].

The objective of this research is to determine how HIV North Society can use collaborative strategies to sustainably increase programming to more communities within a large region in northern Alberta. In addition to submitting my final report to Royal Roads University in partial fulfillment for a Master of Arts in Leadership Degree, I will also be sharing my research findings with HIV North Society, Alberta Health, Public Health Agency of Canada, Alberta Community Council on HIV, as well as through future publications and conferences. A final copy of this report will also be archived in the RRU Library electronically, as well as in the Thesis Canada Portal of Library and Archives Canada.

The Conversation Café questions will explore HIV programming needs within northern Alberta, what types of collaboration already exists and what opportunities for collaboration exist to sustain increased programming. The Conversation Café is expected to take approximately 3 hours to complete.

In addition to submitting my final report to Royal Roads University in partial fulfillment for a Master of Arts in Leadership Degree, I will also be sharing my research findings with HIV North Society, Alberta Health, Public Health Agency of Canada, and Alberta Community Council on HIV. A final copy of this report will also be archived in the RRU Library, as well as in the Thesis Canada Portal of Library and Archives Canada.

Information will be recorded in hand-written, audio recording, photographs, and where appropriate, summarized, in anonymous format, in the body of the final report. At no time will any specific comment be attributed to any individual unless specific agreement has been obtained beforehand. All documentation will be kept strictly confidential. Photographs will be taken of the flip charts, notes created by participants, and the layout of the room. No photos of you will be included in any documentation.

The data will be retained and kept securely in a locked cabinet for the duration of the project. Upon the completion and final acceptance of the thesis report, all data will be retained for a further four years in a secured cabinet in the home of the researcher after which it will be destroyed

Participants of this research project will be able to access the final copy online at [www.hivnorth.org](http://www.hivnorth.org) at the conclusion of this research should they so desire.

HIV North Society employs me as the Executive Director; however, I am conducting this research as a Masters of Arts in Leadership student. I expressly state this to avoid any confusion regarding potential conflict of interest in my role.

You are not required to participate in this research project and your choice of whether or not to participate will have no bearing on your current or future access to services at HIV North. If you do choose to participate, you are free to withdraw at any time without prejudice. Similarly, if you choose not to participate in this research project, this information will also be maintained in confidence.

The direct benefit to you participating in this research is the opportunity to have your voice, thoughts and opinions heard through the Conversation Café. It further allows you to have a say in the implementation of collaborative practices and potential organizational change.

A potential direct risk to participating is people from a broad cross-section of society are being invited to participate in this Conversation Café, including funders, Health and community representatives, municipal government and RCMP. It is therefore possible you may recognize other participants and, for reasons of confidentiality, I will not be able to disclose a participant list in advance. I am also unable to guarantee that others taking part in the Conversation Café will maintain the confidentiality of what is said however I will ask for each participant to sign a confidentiality agreement.

Should you have any questions regarding your rights as a research participant, please contact the University of Alberta Research Ethics Office at [telephone number]. Collect calls will be accepted.

By signing this letter, you declare that you are 18 years of age or older and you give free and informed consent to participate in this project.

- I consent to the audio recording of the Conversation Café
- I consent to have the table charts and flip charts photographed for public presentations or publications
- I commit to respect the confidential nature of the Conversation Café and its participants to ensure no specific comment or experience from the Café can be attributed to any one individual.

Name: (Please Print): \_\_\_\_\_

Signed: \_\_\_\_\_

Date: \_\_\_\_\_