

EXPLORING KEY DETERMINANTS OF HIV/HCV PREVENTION AND RISK:  
VOICES OF ABORIGINAL YOUTH OF PRINCE EDWARD ISLAND

by

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## Abstract

### Background:

Aboriginal communities of Canada have experienced inequities within the historical and social environments. Such inequities have led to an increased vulnerability to health related risks, including risk to Human Immunodeficiency Virus (HIV) and Hepatitis C Virus (HCV) infection. To some extent, research has explored HIV/HCV prevention and risk among Aboriginal communities; however, studies have primarily focused on reported infection rates, adult populations, and urban settings. Thus, the social environment, youth, and those living in rural areas have largely been overlooked within the HIV/HCV discussion.

### Purpose and Methods:

This youth-oriented, community-based research was conducted to identify key determinants of HIV/HCV prevention and risk among Aboriginal youth living in both urban and rural Prince Edward Island (PEI). This research was also conducted to identify applications of this information toward health promotion and HIV/HCV prevention initiatives. Data were collected through six interactive, iterative sharing sessions, which incorporated traditional story-telling, photo-voice, and lessons in cultural photography.

### Findings:

A thematic network analysis of the data yielded emergent core themes and subthemes which were explored in the context of proximal, intermediate, and distal determinants of HIV/HCV prevention and risk. Key proximal determinants identified from the analysis include social/physical contexts, access to information, and geographic location. Intermediate determinants include systems, reducing harms, and culture, while distal determinants include racial discrimination and social isolation, stigma, and self-determination.

### Conclusions:

Four recommendations toward health promotion efforts and HIV/HCV prevention programming among Aboriginal youth of PEI are presented. The findings of this study also highlight the interacting nature of the social determinants of health, the fluidity between risk and prevention, and the importance of strength-based approaches for HIV/HCV prevention and health promotion among Aboriginal youth of PEI.

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## Chapter 1: Introduction

The need for youth-oriented, culturally-relevant, and community-based health promotion programming and research among Aboriginal communities in Canada has been widely acknowledged (Kirmayer, Simpson, & Cargo, 2003; Mundel & Chapman, 2010; Patterson, Jackson, & Edwards, 2006). Contrary to conventional health promotion programs, such upstream, encouraging approaches address health inequities not in isolation, but in light of community strengths and the social determinants which are pertinent to the health of Aboriginal peoples and Aboriginal youth (Kirmayer, Sehdev, Whitley, Dandeneau, & Isaac, 2011; Reading & Wien, 2009). Through this research, 13 Aboriginal<sup>1</sup> youth of Prince Edward Island engaged in a community-based participatory research project, which was planned in partnership with community members and developed to incorporate the ancient tradition of oral story telling in addition to the interactive process of photo-voice. Through stories, photos, and discussion, Aboriginal youth shared their voices to further our understanding on issues concerning prevention and risk toward Human Immunodeficiency Virus (HIV) and Hepatitis C Virus (HCV) infection in the province of Prince Edward Island. Findings from this research are put forth to encourage further focus on strength-based, inclusive health promotion initiatives for the prevention of HIV and HCV among Aboriginal youth of Prince Edward Island.

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<sup>1</sup> The demographic of Prince Edward Island describes Aboriginal peoples living in the province to include First Nations, Métis, and Inuit peoples (Statistics Canada, 2006); therefore, this research invited Aboriginal youth (including First Nations, Inuit, and Métis youth) to participate. When relevant within this document, the term Aboriginal will be used to be inclusive of each First Nations, Inuit, and Metis communities. When referring to specific legislation/programming, the relevant population will be identified.

This research responds to the overrepresentation of Aboriginal peoples among HIV and HCV positive communities in Canada. For instance, while approximately 4% of people in Canada self-identify as Aboriginal, 24% of all HIV infection reports (1998-2008) containing information on ethnicity were linked to Aboriginal peoples. Further, Aboriginal peoples are diagnosed with HIV at a younger age than peoples of other ethnicities, and are overrepresented among those living with HCV, often seen as a precursor to HIV (Public Health Agency of Canada, 2010). However, while epidemiological surveillance is a significant piece of the HIV/HCV discussion, it must be noted that the reporting of infection rates fails to acknowledge the essential context in which risk and infection takes place.

Environmental factors surrounding HIV and HCV prevention and risk among Aboriginal peoples are related to historical and present inequities (Reading & Wien, 2009; Smylie, 2004). Understanding health in light of such past and present inequities is an approach that corresponds with the social determinants of health framework. This framework is defined by the World Health Organization (WHO) (2007) as the conditions in which people are born, grow, live, work, and age; it is defined as the social, economic, political, cultural, and environmental predictors of health. Further, this framework views health inequalities as a production of stratification in society, a function of the unequal distribution of goods, services, power, and income (Marmot, Friel, Bell, Houweling, & Taylor, 2008; World Health Organization, 2007). Thus, in order to address health inequities, one must first understand the social determinants which are their cause.

The Public Health Agency of Canada (2010) has reiterated the importance of addressing health disparities, including those pertaining to HIV/HCV among Aboriginal

peoples in Canada, in light of the social determinants of health. Researchers have explored HIV/HCV prevention and risk in this light, for example examining determinants of sexual risk-taking and needle sharing behaviours (Duncan et al., 2011; Strathdee et al., 1997; Strathdee et al., 1998). Still, the literature calls for continued consideration of the social determinants of HIV and HCV prevention and risk among Aboriginal peoples in Canada (Majumdar et al., 2004; Rhodes, Singer, Bourgois, Friedman, & Strathdee, 2005). Researchers have also emphasized the importance of reflexive, action-orientated, and relationship-based approaches when exploring HIV and HCV among Aboriginal communities (Patterson, Jackson, & Edwards, 2006; Steenbeek, Bailey, & Simandl, 2013).

The majority of research surrounding HIV/HCV risk and prevention among Aboriginal youth has been conducted only in the most populated provinces (namely British Columbia, Ontario, and Alberta), with an emphasis on urban-based communities (Majumdar et al., 2004; Mehrabadi et al, 2008; Pearce et al., 2008). This has been justified, in part, given that many Aboriginal youth are migrating to urban settings, potentially becoming exposed to risks of street involvement and injection drug use (Health Canada, 2004). However, this research fails to consider Aboriginal youth who remain in rural areas and who live in largely under-resourced as well as under-researched provinces.

A recent initiative involving Aboriginal youth living in both rural and urban areas in Canada is the *Taking Action! Project: Art and Aboriginal Youth Leadership for HIV Prevention*. This national project involved youth-led workshops in six Aboriginal communities across Canada, using drama, painting, photography, carving, and other arts-

based avenues to create projects inspired by HIV prevention topics. Such topics included early colonization, ongoing colonization, resistance, reclaiming culture, Aboriginal cultural knowledge, and healthy sexuality (Flicker et al., 2012). The *Taking Action!* project is continuing into a second phase, using digital storytelling as a tool to talk about HIV/AIDS information and prevention (Taking Action, 2013). From the perspectives of Aboriginal youth, the findings of *Taking Action!* part one tell of the importance of including culture and youth-focused means, such as art, in HIV prevention programs (Flicker et al., 2012).

Additional HIV/HCV prevention resources and initiatives have incorporated youth-friendly, cultural elements. For example, the Canadian Aboriginal AIDS Network offers various resources, including a manual for *Assessing Community Readiness & Implementing Risk Reduction Strategies*, and a toolkit for community mobilization toward HIV prevention (Canadian Aboriginal AIDS Network, 2012; Stratton, Jackson, & Barlow, 2006). Cultural elements have also been incorporated into prevention initiatives in the province of Prince Edward Island, including oral storytelling (O'Neill, 2008). Oral story telling is an ancient tradition held within many Aboriginal communities, in which communities use stories to share insight on the natural world, survival, values, and the continuum of life experiences (Carlson, 1994). Further, storytelling is traditional to the Mi'kmaq peoples of Atlantic Canada, exemplified by the well known songs and stories of Rita Joe, a Mi'kmaq poet who has shared the stories of her daily life. These include experiences through foster care, residential schooling, and poverty (Rita Joe, 1996). Given the context of overrepresentation of Aboriginal peoples, and youth specifically, among HIV/HCV positive communities, there is a continued need for further HIV/HCV

prevention efforts incorporating cultural traditions in both urban and rural settings in Canada (Public Health Agency of Canada, 2010).

### **Purpose of Study**

In keeping with the principle of community-based research, this study was conducted in partnership with community advisors to explore the perceived key determinants of HIV and HCV risk and prevention among Aboriginal youth (16-24 years) in the province of Prince Edward Island, and to explore the differing dimensions of these determinants between urban and rural settings. This study was also conducted in order to examine the ways by which findings might be utilized in the development of health promotion initiatives, including HIV/HCV prevention programming and policy. The research questions which guided this study are as follows:

1. What are the key social determinants of HIV and HCV prevention specific to Aboriginal youth living in rural and urban Prince Edward Island? What are the key determinants of HIV and HCV risk?
2. In what ways can this knowledge be integrated into HIV and HCV prevention?

### **Theory, Methodology, and Significance of Study**

Elements of this study were informed by the theoretical orientation of critical indigenous pedagogy, an approach which considers both the moral and political nature of all inquiry. In addition, critical indigenous pedagogy recognizes the transformative power of indigenous knowledge in achieving social justice purposes, as well as the processes by which this knowledge is created. This pedagogy also employs methods critically, seeking dialogue, community involvement, and the use of participatory and empowering approaches (Denzin & Lincoln, 2008).

Critical indigenous pedagogy calls for a reflexive research approach to research (Denzin & Lincoln, 2008). Thus, as a researcher, I have considered the ways by which my own assumptions, experiences, and values interact with the research process and with the communities with whom I was working. I have also reflected on my role as a youth researcher exploring youth health in my home province of Prince Edward Island, and I have reflected on my role as a non-Aboriginal woman studying HIV/HCV prevention among Aboriginal peoples. I have respectively engaged with Indigenous literature, seeking to learn about Aboriginal cultural traditions of Canada, and Mi'kmaq traditions of Eastern Canada. Indeed, this research has been a personal learning experience, as I have learned from written and oral stories, the research experience, cultural events, and from valuable experiences building relationships with Aboriginal peoples in Prince Edward Island. Finally, I sought to respect the methodological implications of a critical indigenous orientation through bridging culturally relevant and youth-oriented approaches into the research process, such as traditional storytelling, photo-voice, and community youth facilitators.

This study was also guided by a community-based research framework, which incorporates the involvement of community members in all aspects of the project and recognizes the unique strengths that each member brings to the research process (Minkler & Wallerstein, 2003). Meeting the criteria of community-based research, this study was discussed with a community representative before any steps in the research process were taken. After interest was expressed, a community advisory committee was formed, including: a representative from the Native Council of PEI; a representative from Healing Our Nations; a community elder; youth community members; and an adult community

member. The community advisory committee was consulted in the development of the research proposal, and was also involved in carrying out the project, analysing data, and planning the dissemination of findings.

Specifically, thirteen Aboriginal youth from Prince Edward Island, 17-21 years in age, took part in a series of iterative sharing sessions. Six youth from urban areas of Prince Edwards Island took part in three urban sharing sessions, while seven youth of rural areas took part in three rural sharing sessions. In the first urban and rural sharing sessions, youth explored community-specific social determinants of HIV/HCV risk and prevention. The second urban and rural sharing sessions, informed by the first, invited youth to use a photo-voice activity to illicit story telling of applicable accounts, events, and environments. Finally, the third urban and rural sharing sessions were used to explore how stories and information offered in the previous sessions might be incorporated into future health promotion and HIV/HCV prevention initiatives.

Given the social determinants of health perspective used to help frame this research, this study may have programming and policy implications. According to a study conducted in Prince Edward Island, members of Health and Social Services in the province, as well as the general public, recognize the importance of many social factors (in addition to formal health care) as important determinants of health. Personal health practices, however, remain the highest concern of these stakeholders (Eyles et al., 2001). Although conducted over a decade ago, this study suggests that there is both a foundation as well as a need for work surrounding the social determinants of health among the general population of Prince Edward Island. Still, this need is largely unexplored within Aboriginal communities. Thus, this research project was carried out to better understand

social determinants among Aboriginal youth living in Prince Edward Island, particularly those determinants relating to HIV and HCV prevention and risk. Dissemination events are anticipated in order to transform this understanding into youth-friendly, strength-based, and culturally-relevant health promotion and HIV/HCV prevention efforts.

### **Summary of Chapter 1**

This chapter reviewed the context within which this study is placed. This chapter briefly introduced the relationship between the social determinants of health and the overrepresentation of Aboriginal peoples within HIV/HCV positive communities. Additionally, this chapter summarized the purpose of this research, its methodology, and significance. Chapter 2 will provide an in-depth discussion of applicable literature surrounding this topic.



## **Chapter 2: Literature Review**

This chapter will begin with an overview of epidemiological surveillance surrounding HIV/HCV among Aboriginal communities, and will then review factors related to HIV/HCV risk. This chapter will also draw upon the social determinants of health which have influenced this surveillance, and will detail determinants involved in HIV and HCV prevention. Finally, this chapter will consider ways in which strength-based approaches and the social determinants of health can be incorporated into youth-relevant, HIV/HCV related health promotion efforts, including research, policy, and programming, within Aboriginal communities in Canada.

### **Background: Epidemiological Surveillance and HIV/HCV Risk**

Aboriginal communities are overrepresented within health inequities, including that of HIV and HCV infection. Additionally, rates of HIV among Aboriginal peoples continue to rise; the estimated number of Aboriginal persons living with HIV (including AIDS) in Canada rose from 64,000 in 2008 to 71,300 in 2011 (an 11.4% increase) (Public Health Agency of Canada, 2011b). There are also an estimated 242,500 individuals living with HCV in Canada, with the reported rate of acute HCV infection for Aboriginal peoples approximately five times higher than for persons of other ethnicities (Public Health Agency of Canada, 2009).

Within the Atlantic region of Canada (encompassing New Brunswick, Nova Scotia, Newfoundland and Labrador, and Prince Edward Island), the rate of HIV diagnosis among the general population has remained relatively stable between 2002 and 2010 (Public Health Agency of Canada, 2010). However, in Prince Edward Island (PEI), there has been an increase in the number of reported HCV cases among the general

population. For instance, 33 positive HCV tests were reported in 2006, while 56 positive HCV tests were reported in 2010 (Public Health Agency of Canada, 2011a). Although data in the Atlantic region of Canada is not reported separately by ethnicity, the figures noted above beg for a greater understanding of HCV in the Atlantic Provinces. In addition, the national figures illustrate the need to better understand HIV and HCV, and particularly the contextual determinants of prevention and risk, among Aboriginal communities in order to improve health promotion and HIV/HCV prevention efforts.

While epidemiological surveillance is important in HIV/HCV prevention, it must be noted that this surveillance does not acknowledge the contexts in which risk and infection takes place. Thus, the following section will introduce these contexts, including the various means through which infection occurs.

**HIV/HCV risk.** The HIV/HCV risk environment is deeply related to the statistics noted above. The general risk environment of HIV infection can be defined as a “space, whether social or physical, in which a variety of factors exogenous to the individual interact to increase vulnerability to HIV” (Rhodes et al., 2005, p.1026). Such social and physical environments influence avenues for risk, including modes of transmission such as injection drug use and having unprotected sex.

Among Aboriginal peoples in Canada, injection drug use is the most commonly identified mode of HIV transmission, accounting for 66% of positive HIV reports in 2008. Heterosexual contact is also a major mode of transmission, accounting for almost 23% of positive case reports, while 9% of positive reports were attributed to men who have sex with men. Further modes of transmission include perinatal transmission and transmission through contaminated blood or blood products (Public Health Agency of

Canada, 2010). With regard to HCV, the predominant exposure category is injection drug use among all racial and ethnic groups. In fact, injection drug use is associated with 70-80% of all new HCV cases, with remaining cases attributed to: sharing equipment for inhalation drug use (crack pipes, straws); tattooing or piercing with contaminated equipment; sharing of personal hygiene items (razors, toothbrushes) with an individual living with HCV; and occupational blood exposure (Public Health Agency of Canada, 2009). Being that the primary modes of HIV/HV transmission among Aboriginal peoples include sexual contact and injection drug use, it is important to explore the topics of healthy sexuality and substance use in greater depth.

***Sexuality.*** Adult sexual outcomes are rooted in early life, suggesting the importance of developing healthy sexual lifestyles in the years of childhood and youth (Tolman & McClelland, 2011). Healthy sexual practices among children and youth are often promoted through community education, cultural programs, peers, the media, and school education (Kirby, Laris, & Rolleri, 2007; Kirby, Laris, & Rolleri, 2009; Levine, McCright, Dobkin, Woodruff, & Klausner, 2008). Although sexuality-based education is provided to youth through these various means, literature surrounding this subject is largely consumed by discussion of the school system. This is pertinent to the concerns of Aboriginal young people involved in the public school system, as most Aboriginal youth in Canada attend schools wherein culture is separated from educational settings. Researchers have addressed this concern, suggesting that culture be incorporated into education programs, and specifically sexuality-based programs being provided to young Aboriginal people (Devries, Free, Morison, & Saewyc, 2008; Majumbar et al., 2004).

Indeed, incorporating culture into educational curriculums has been associated with increased condom use among young Aboriginal men in Canada, aged 12-20 years (Devries et al., 2008). From this, it is suggested that educational approaches to sexuality move beyond the individual level, and integrate cultural, social, and structural elements into curriculum material. Further, the importance of cultural competence is emphasized in this discussion, a notion that can be described as the capacity to understand and communicate with individuals from a variety of cultures in an appropriate and effective manner (Bustamante, Nelson, & Onwuegbuzie, 2009; Devries et al., 2008; Lustig & Koester, 2002). It is suggested that cultural competence be developed by educational leaders, both within the school system and within community programs, in order to facilitate learning among diverse youth populations (Bustamante et al., 2009).

In addition to the involvement of culture, there exists a spectrum of additional approaches to promoting healthy sexuality among young people. A scan of evaluations measuring the impact of curriculum-based sex and HIV education programs (in such countries as the United States, Canada, Norway, Spain, Belize, Mexico, and South Africa) found that two thirds of all programs evaluated increased condom or contraceptive use. While this is an important success, it is interesting to note that program material largely encouraged abstinence as a means for HIV prevention (Kirby, Laris, & Rolleri, 2007). This brings light to the importance of curriculum approaches, that youth's choice and curiosity be respected, while peer-to-peer experiences (i.e., peer pressure) be considered.

Additional factors, beyond educational programming, have also been associated with sexual health. Such factors include: history, individual development and

physiological factors, the social environment, family connectedness, living on reserve (among First Nations communities), and drug use (Devries et al., 2008; Donovan & Ross, 2000). The latter factor, and specifically injection drug use (IDU), is discussed in the following section.

***Injection drug use.*** IDU use is highly related to HIV and HCV infection (Strathdee et al., 2010). For example, 67% of HCV cases among Aboriginal peoples reported between 2002 and 2008 were linked to IDU. Factors influencing HIV and HCV risk among injection drug users include borrowing/sharing injecting paraphernalia (needles, syringes, rinse, spoons, cotton filters), and frequency of injection (Public Health Agency of Canada, 2010). Age of first injection also influences HIV and HCV risk, which emphasizes the importance of prevention efforts and harm reduction efforts aimed at youth.

In Canada, the age of an individual's first injection varies by community, but generally occurs in late adolescence or early twenties. The average age of an individual's first injection in Canada is 21.4 years; however, 30% of people who inject drugs begin injecting at the age of 16 years or younger. Additionally, Aboriginal youth report initiating injection drug use at an earlier age on average than non-Aboriginal youth (Health Canada, 2006; Public Health Agency of Canada, 2010).

In the past, it has been suggested that vulnerability to IDU-related HIV and HCV exposure among racial and ethnic minorities may be related to barriers in accessing culturally appropriate harm reduction services and other health services. For instance, First Nations peoples living on reserve encountered such obstacles as distance, cultural divisions, unavailability of methadone programs on reserve, and a lack of home-based

services (Mainline Needle Exchange, 2000). More recently, however, access to harm reduction services within Aboriginal communities in Atlantic Canada has increased with positive momentum. For example, the Native Council of Prince Edward Island has offered an HCV prevention program for Aboriginal youth, providing HCV prevention education, resources, and activities for Aboriginal youth living in PEI. AIDS PEI partners with this program, seeking to also meet the HIV prevention needs of Aboriginal youth in the province (O'Neill, 2008).

More broadly, Aboriginal AIDS Service Organizations serving Atlantic Canada have been supporting harm reduction initiatives for over a decade. For example, one of such organizations hosted a conference in 2012, exploring local harm reduction initiatives such as methadone treatment and next steps for expanding such initiatives (Healing our Nations, 2012). Further, according to a recent scan on harm reduction policies in Atlantic Canada, formal policy documents relating to methadone programming were released in all four Atlantic provinces between 2005 and 2009 (Tiesmaki, 2011). Thus, there is an encouraging environment within Atlantic Canada wherein discussion surrounding harm reduction, methadone treatment, and needs of Aboriginal communities and Aboriginal youth are being increasingly explored.

### **The Social Determinants of Health**

Given the numerous factors that are associated with HIV and HCV risk among Aboriginal peoples, it is important to approach health promotion efforts surrounding the prevention of HIV and HCV in light of the social determinants of health framework. The social determinants encompass circumstances, environments, structures, systems, and institutions that affect both the development and the maintenance of health (Reading &

Wien, 2009). Importantly, scholars have advocated for a social determinants-oriented approach to policy and programming aimed at diminishing health inequities (Graham, 2004; Marmot, 2000). For this to be accomplished, determinants of unique health related risks must be better understood, particularly those pertaining to Aboriginal communities and Aboriginal youth (Canadian Aboriginal AIDS Network, 2010).

**Social determinants of Aboriginal peoples' health.** As suggested by researchers in Canada, the conventional social determinants framework does not reflect the unique health environment of Aboriginal peoples (Reading & Wien, 2009; Smylie, 2004). In addition, little is known with regard to the influence of these social determinants on the wellbeing of Aboriginal communities (Reading & Wien, 2009). Nonetheless, it is certain that there are social predictors of Aboriginal peoples' health that are unique from those of the general population in Canada (Lavallee & Poole, 2010; Smylie, 2004).

History and colonization remain determinants of Aboriginal peoples' health in the present time. The sociohistorical context of the Aboriginal population in Canada involves processes of European colonization dating from the sixteenth century, with most on-going colonial processes experienced today stemming from the Gradual Civilization Act of 1857, The Constitution Act of 1867, and subsequent Indian Act (Lavallee & Poole, 2010; Smylie, 2000). Such legislation intentionally authorized the removal of First Nations communities, outlawed First Nations ceremonies, and supported the removal of First Nations and Inuit children for placement in residential schools where culture, language, and traditions were suppressed. Further, residential schools were the site of physical abuse, emotional abuse, sexual abuse, and neglect. The legacy of the residential

school program is a continuing cycle of intergenerational trauma<sup>2</sup>, which highlights how the trauma of being removed from family influences generation after generation (Smylie, 2000).

Colonization within First Nations communities in Canada continued as the federal government transferred the responsibility of First Nations and Inuit welfare to provincial jurisdictions in 1951 (Fournier & Crey, 1997). This shifted the historical nation-to-nation relationship between the Crown and First Nations without consultation or agreement from the First Nations. An Outcome of this transfer is highlighted in the context of child welfare. Governmental child care social workers, who were not provided with the skills or resources needed to understand community dynamics or to address the legacy of the residential schools, including intergenerational grief and poverty, accessed children at risk and defaulted to the forced removal of First Nations children from their homes, communities, and cultures (Blackstock & Trocmé, 2005). Known as the '60s scoop', the mass relocation of First Nations children into adoptive families, foster care, and group homes was an inappropriate and ineffective solution to meet the needs of Aboriginal children and to respond to the multi-generational pain experienced by First Nations peoples. Indeed, this practice disrupted valued family traditions, severed family networks, and upset relationships that were meaningful providers of support, respect, and education (Blackstock & Trocmé, 2005; Carlson, 1994).

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<sup>2</sup> The effects of experiencing trauma are often transmitted within and across generations, and throughout communities (Atkinson, Nelson, & Atkinson, 2009). The trauma experienced by Aboriginal communities through colonial processes (i.e., First Nations and Inuit children's experiences of abuse and neglect within the residential school program) has affected generation after generation (Smylie, 2000).



The present effects of colonization are expressed in many health disparities (Smylie, 2004). According to Reading and Wien (2009), there are various mechanisms through which colonization influences health. Such mechanisms include environmental relationships, social policies, and political power. Of these three mechanisms, social policies and political power are of most relevance to this research project. While there is a dearth of literature detailing such mechanisms, it can be certain that the legacy of the residential school program, expressed through intergenerational trauma, influences each emotional, spiritual, mental, and physical aspects of health of First Nations and Inuit communities. For example, the residential school program has resulted in cross-generational post-traumatic stress, depression, anxiety, and substance abuse, which in turn create vulnerability to additional illness (Bombay, Matheson, & Anisman, 2009; Czyzewski, 2011).

History and colonization also interact with various other determinants of health, demonstrating the complex interactions and interconnectedness of the social determinants of health unique to Aboriginal peoples. Reading and Wien (2009) put forth an *Integrated Life Course and Social Determinants Model of Aboriginal Health* as a conceptual framework for understanding relationships between health dimensions and social determinants specific to Aboriginal communities. This model suggests a holistic understanding of health and wellbeing, reflecting the ideologies held within Aboriginal populations. In particular, this model highlights the importance of perceiving and addressing health as a phenomenon that encompasses physical, spiritual, emotional, and mental dimensions (Hunter et al., 2006; Reading & Wien, 2009).

Reading and Wien (2009) also draw upon specific proximal, intermediate, and distal determinants that are unique to the health of Aboriginal communities. Proximal determinants are noted to be characteristics of an individual's immediate surroundings that have a direct impact on physical, emotional, spiritual, or mental health. Proximal determinants include employment, income, food insecurity, and the physical environment (such as living conditions, encompassing crowding and sanitation). Aboriginal peoples living in remote and reserve communities face challenges related to proximal determinants, including overcrowded dwellings, poor housing ventilation, and consequent mould. Such factors have been associated with health issues such as asthma and allergies among Aboriginal children (Strachan, 2000).

Intermediate determinants of health involve community infrastructure, resources, and capacities (health care systems, educational systems, environmental stewardship, and community infrastructures, resources, and capacities). Often, intermediate factors are the origin of proximal determinants. Intermediate determinants of Aboriginal peoples' health are unique, encompassing barriers to accessing geographically available and culturally appropriate health and educational services. For instance, First Nations adults living on reserve in Canada face numerous barriers in accessing health related services, including: a lack of transportation, long wait lists, culturally inappropriate services, difficulty receiving traditional care, service providers unavailable in the geographic area, high costs of services or transportation, and difficulty in accessing and/or affording child care (Reading & Wien, 2009).

Distal determinants of health consist of broader historical, political, social, and economic contexts. Such determinants "have the most profound influence on the health

of populations because they represent political, economic, and social contexts that construct both intermediate and proximal” dimensions (Reading & Wien, 2009, p.20). Distal factors encompass racism, social exclusions, and self-determination. Distal determinants are also particularly germane to the health of Aboriginal communities, as they encompass the ongoing effects of European colonization (Smylie, 2004).

**The life course approach.** The social determinants of health can be conceptualized in several ways, each encompassing the many connections amongst the determinants of health, and thus naturally corresponding to the holistic foundations of Aboriginal communities. Reading and Wien’s (2009) *Integrated Life Course and Social Determinants Model of Aboriginal Health* is specifically a life course approach to the social determinants of health. The life course approach is an approach to health promotion which recognizes that many determinants act upon health and suggests that health is an adaptive process, influenced by cumulative risk and protective factors. Both timing and sequence of events and experiences are noted to influence the development of health, both for individuals and also for populations. Ultimately, this approach to health is built upon the understanding that health throughout one’s early life is connected to health and wellbeing in mid and later life, a notion that reflects the continuum of life processes (Halfon & Hochstein, 2002).

**Social determinants and HIV/HCV risk.** HIV/AIDS within Aboriginal communities has been studied in light of the social determinants of health framework on several occasions. The Cedar Project, for instance, is a community-based research initiative conducted in British Columbia that seeks to address HCV and HIV related vulnerabilities among Aboriginal youth within the context of historical trauma and

colonization. The project focuses equally on both HIV and HCV, as HCV is considered a potential precursor to HIV infection. To date, The Cedar project has published numerous articles which detail findings involving the interconnectedness of historical trauma, sexual abuse, gender, HIV and HCV vulnerabilities, and HIV infection (Christian & Spittal, 2008; Mehrabadi et al., 2008; Pearce et al., 2008; Spittal et al., 2007). Similarly, Larkin et al. (2007) have examined HIV risk and systemic inequities among Aboriginal youth in the Toronto area, finding social determinants of risk to include: the presence of HIV/AIDS in the participants' own communities; substance and sexual abuse; experiences of colonialism; and poverty.

Specific intermediate determinants of HIV and HCV risk have also been examined, and specifically HIV testing and care among Aboriginal youth. For example, Mill and colleagues (2008) conducted surveys and interviews among Aboriginal youth living across Canada who were recruited through urban AIDS service organizations and other community organizations. Mill and colleagues (2008) found the most common reason to access HIV testing was pregnancy and having sex without a condom, while reasons for not accessing testing included perceptions of being at low risk to HIV or never having had sex with an infected person. In total, approximately half of the surveyed youth (n=413) had accessed HIV testing. Youth participating in this study were at the time residing in Vancouver, Edmonton, Winnipeg, Ottawa, Toronto, Montreal, Halifax, Labrador, and Inuvik (Mill et al., 2008).

While the majority of research surrounding HIV and HCV risk among Aboriginal youth has been conducted in urban Canadian settings, researchers have examined HIV testing and risk behaviours among rural adults of Aboriginal descent in British Columbia.

Notably, off-reserve residents were significantly more likely to use illicit drugs than reserve residents, and were also more likely to be tested for HIV (Wardman et al., 2006). Such findings illustrate the differing dimensions of risk between off-reserve adult residents and adults living on reserve.

Specific to risk involving IDU, additional proximal, intermediate, and distal determinants of HIV and HCV have been identified. Select social determinants of IDU include population mixing, neighbourhood deprivation and/or disadvantage, and specific injecting environments (such as shooting galleries and prisons). Further factors identified to influence risk include peer/social pressure, political and/or economic transition, community policy/programming, stigma, and political, social, and economic inequities related to ethnicity, gender, and sexuality (Rhodes et al., 2005). Such determinants, however, relate to the general population and are not specific to Aboriginal communities.

The above discussion exemplifies the many relationships between the determinants of health and risk to HIV/HCV infection. Thus far, this discussion has focused upon risk factors that increase one's likelihood of HIV and HCV infection; however, is it crucial to also consider protective factors that decrease this risk.

### **A Strength-Based Approach to Health Promotion**

A growing field of study that emphasizes strengths, successes, values, and hopes as a means for personal and organizational change is that of appreciative inquiry. This inquiry examines “what gives life to human systems when they function at their best”, a strength-based approach that is applicable in prevention research and programming, particularly in identifying factors that mitigate health related risks (Whitney, Trostenlloom, & Cooperrider, 2010, p.1). Notably, this inquiry is founded on the notion

that people, both individually and collectively, have unique gifts, skills, and contributions to life. Additionally, this inquiry suggests that attention can be shifted from the problem to lift up existing strengths, ideals, values, and successes in order to create possibilities and solutions for the future (Whitney et al., 2010).

Appreciative inquiry corresponds with the strength-based approach to Indigenous health promotion, and also corresponds with the social determinants model of health. Like appreciative inquiry, the strength-based approach to Indigenous health promotion advocates for the support of existing positive determinants of health within communities in order to promote better well-being. In an urban-based study of Aboriginal peoples' well being, several community strengths were identified, including individuals' commitment to community, neighbourhood networks, community organizations, and community events (Brough, Bond, & Hunt, 2004). In addition to supporting such community structures and characteristics, it has also been suggested that positive community perspectives, values, and traditions be integrated into health services and research initiatives (Browne & Varcoe, 2006; Hunter et al., 2006; Smylie & Anderson, 2006). Specifically, incorporating concepts of holism, balance, and cultural healing is recommended to counter the influences of colonization in the lives of Aboriginal peoples (Hunter et al., 2006; Larkin et al., 2007).

Incorporating community culture and values into health services and research initiatives necessitates the involvement of community members in policy, programs, and research development. Community-based participatory research necessitates this involvement, such that community members are involved in each step of the research process, including project development, analysis, and dissemination of findings.

Community-based participatory research is also important in ensuring that self-determination, needs, cultural values, and traditions of Aboriginal communities be respected (Minkler & Wallerstein, 2003).

Likewise, incorporating the strengths of Aboriginal communities in health promotion initiatives requires that researchers and policy makers acknowledge Indigenous resilience and autonomy. Indeed, Aboriginal communities have demonstrated resilience throughout colonial activities, incorporating traditional approaches into various health initiatives (Andersson & Ledogar, 2008; Majumdar et al., 2004). An initiative specific to the province of PEI is The Native Council of Prince Edward Island's *Hep'd Up On Life* program. Developed in 2007, this program sought to build HIV and HCV prevention capacity among PEI Aboriginal youth. *Hep'd Up On Life* continues today and has grown to include various program components, one being the passing of knowledge from peer to peer in the form of oral story-telling, a traditional means of conveying wisdom used by the youth's ancestors (O'Neill, 2008).

### **Literature Gap**

In recent years, the inclusion of Aboriginal culture and Indigenous approaches in research and programming has become a practice of increasing popularity. In fact, this practice has been incorporated into research exploring determinants of Aboriginal peoples' health, as well as determinants of HIV and HCV prevention and risk. Of note, such literature is largely absent in rural settings and also in the Atlantic Provinces (Pearce et al., 2008; Larkin et al, 2007). Therefore, there is a need for culturally competent, strength-based inquiry into the key determinants of HIV and HCV prevention and risk

among Aboriginal peoples in rural and under researched provinces, and particularly among youth.

### **Summary of Chapter 2**

This chapter reviewed the overrepresentation of Aboriginal peoples within HIV and HCV positive populations in Canada, and summarized various colonial activities which have influenced this overrepresentation. This chapter also detailed factors involved in HIV prevention and risk, and considered ways in which strength-based approaches and the social determinants of health framework can be incorporated into youth-friendly and culturally relevant health promotion efforts among Aboriginal communities in Canada. Finally, this chapter identified the literature gap addressed by this research.



### **Chapter 3: Methodology**

This chapter will detail the theoretical orientations, methodological approach, and methods employed in this study. In addition, this chapter will discuss intended actions for knowledge dissemination, potential study limitations, and ethical considerations.

#### **Theoretical Orientation**

A theoretical orientation, or paradigmatic stance, represents a set of beliefs surrounding the nature of the world and the relationships occurring within it (Guba & Lincoln, 1994). A first theoretical orientation which guided this research is that of critical theory. According to Guba and Lincoln (1994), this theoretical orientation seeks the “transformation of the social, political, cultural, economic, ethnic, and gender structures that constrain and exploit humankind” (p. 113). Central to critical theory are the concepts of activism and advocacy, as well as various assumptions related to ontology and epistemology. First, perceptions of reality are considered to be influenced by social, political, economic, cultural, ethnic, and gender structures, each developing over time. Second, research findings are considered to be subjective, mediated by the inquirer’s values. Finally, critical theorists acknowledge the interaction between the researcher and the participants, therefore encouraging dialectical methods throughout the research process (Guba & Lincoln, 1994).

While there are several different interpretations of critical theory, the interpretation put forth by Guba and Lincoln (1994) is most appropriate for this research. This interpretation bridges neo-Marxism, feminism, materialism, and participatory inquiry into a single perspective that acknowledges the numerous and diverse influences on reality (Guba & Lincoln, 1994). Importantly, this viewpoint coincides with the social

determinants of health framework which recognizes the many factors affecting health and well being.

An element of critical theory that is of importance within this study is the desired outcome of transforming structures that historically and currently constrain humankind. Most often, it is assumed that the investigator understand a priori what transformations are needed; however, for the purpose of this research, the need and nature of transformations will be determined by those whose lives are most affected, the participants themselves (Guba & Lincoln, 1994).

Elements of this research were further guided by critical indigenous pedagogy (CIP), an orientation which merges critical and indigenous approaches. CIP recognizes the transformative power of indigenous knowledge, as well as the processes by which this knowledge is created. While CIP is indeed a theoretical orientation, this pedagogy also provides multiple methodological criteria to be met. For instance, inquiries guided by CIP must employ methods critically, seeking to use emancipatory, ethical, transformative, participatory, and empowering approaches. As such, this study involved the meaningful and active participation of both community members and youth participants, and also involved traditional oral storytelling in addition to teachings in cultural photography. Further, inquiries guided by CIP must be dedicated to justice and equity, and the researcher must reflect critically, considering the ways in which he or she promotes self-determination for the research participants (Denzin & Lincoln, 2008). Thus, as a researcher, I have reflected on my role as a non-Aboriginal youth researching HIV/HCV prevention among Aboriginal youth in my home province of PEI.

## **Researcher Reflexivity**

As a researcher, I have made ontological, epistemological, and axiological assumptions in choosing the paradigmatic orientations of critical theory and CIP (Creswell, 2007). Such assumptions are a function of my experiences, background, and beliefs, which have also contributed to my decision in choosing this particular research topic. For instance, I grew up in rural PEI, in a small community of approximately 250 people. This community is situated relatively close to one of four Mi'kmaq reserves in PEI and thus I built relationships with Aboriginal community members throughout my upbringing. Perhaps consequently, I became interested in Aboriginal culture during the course of my adolescent years. Today, I find myself passionate about the health inequities experienced by Aboriginal peoples and I am continuously gaining understanding into the connections between such inequities and political, social, and economic events of the past and present. As a result, I have chosen to study the social determinants of Aboriginal peoples' health, specifically for youth, in my home province of PEI.

In accordance with Guba and Lincoln's (1994) critical theory and CIP, and in partnership with community advisors, I have sought to critically assess the methods to be used in this research study. Having a background in basic science research (biology and psychology), I sought to engage with Indigenous literature and with community members in order to reflect upon and learn about the most suitable approaches to the study of HIV/HCV prevention among Aboriginal youth of PEI. With community and academic partners, we decided to incorporate sharing sessions, oral storytelling, and photo-taking into the research process (described more fully in later sections), in order to embrace interactive, oral, fluid, and experiential ways of knowing and learning. We also decided

to invite a youth community member to facilitate each sharing session, in order to acknowledge and address power differentials which often arise between the researcher and participants.

As a researcher, I have recognize my status as a non-Aboriginal woman conducting research with a community historically exploited by research processes. Throughout the course of this project, I have adapted a reflexive approach, acknowledging the ways in which my own assumptions, values, and culture interact with the research process and the community with whom I have been working. Further, I have acknowledged my role as a Master's student, a role which poses challenges in equitably involving community members in all stages of the research process (for instance, I am responsible for independently writing and presenting proposal and thesis material). Recognizing this limitation, I have sought to involve community members in a meaningful way throughout the entirety of this research process. I have also sought to understand the traditions of the Aboriginal community of PEI, and to build lasting relationships within this community. This relates to the objective of mutual benefit put forward in this research, in which the research process will contribute to my experiences, understanding, and knowledge as a researcher while also informing the prevention initiatives of the community.

Concerning 'insider-outsider' dynamics, I remain an outsider with regard to ethnicity and culture; however, as a youth researcher from PEI studying the health of youth living within this province, I have experienced insider relationships with the participants of this study who were my peers. In this way, I have similar youth- and locality- related characteristics and experiences as the participants themselves. Indeed,

there exist challenges and benefits of being both an insider and an outsider within the research process. In addition, this insider-outsider relationship is often perceived to be dichotomous, wherein the researcher is perceived exclusively as one or the other.

However, my experiences with this research project illustrate the blended nature of these constructs. That is, my experiences demonstrate that it is indeed possible to act as both an outsider *and* an insider throughout the research process. This concept is termed as the 'space between' by researchers Dwyer and Buckle (2009), who suggest that the space between 'insider' and 'outsider' is in fact a space which may enable researchers to consider perspectives common to both the participant community and the surrounding community. Dwyer and Buckle discuss the importance of merging dichotomous views, such as the insider-outsider view, in order to embrace and explore the complexity surrounding various perspectives and the possible space between them (2009).

### **Methodological Approach**

This research was guided by a community-based participatory research approach, accompanying Guba and Lincoln's (1994) critical theory which supports active dialogue between the researcher and participants. A community-based participatory research approach is important in ensuring that self-determination, needs, cultural values, and traditions of Aboriginal communities be respected, as this approach involves community members in all aspects of the research project. Of note, this approach recognizes the unique strengths that each individual brings to the research process, an element that is particularly suitable for the strength-based recommendations put forth in the literature surrounding research with Indigenous communities (Minkler & Wallerstein, 2003).

A community advisory committee was formed in order to facilitate the community-based participatory research process. Also, with community-based research involving Aboriginal peoples, it is important that community advisory committees represent the many voices shared within the community. As such, various community members were invited to take part in this committee, including: a representative from the Native Council of PEI; a representative from Healing Our Nations; a community elder; youth community members; and an adult community member. This project was carried out in close partnership with this committee, and discussions occurred in the development, execution, analysis, and planned dissemination of the research project.

The distinction between community-based participatory research and other means of community driven research is recognized in this study. Indeed, researchers often encounter obstacles throughout the community-based participatory research process, causing diversion from meaningful community involvement in all stages of the research process. Such obstacles can involve challenges in community inclusion in selecting research questions (as a result of conflicting researcher expertise and community interests), insider-outsider tensions, limitations on community involvement, and dilemmas in disseminating findings. Recognizing such potential obstacles prior to data collection has been helpful in carrying out a community-based participatory research study, involving community representatives in a meaningful way throughout all stages of the project (Minkler, 2005). Additionally, a research collaboration agreement (modified from that created by the Canadian Aboriginal AIDS Network) was developed between the community advisory committee and myself (see Appendix A). This agreement formally iterates the community's right to the ownership, control, access, and possession

of the research process, data, and findings. In addition, this agreement recognizes the requirements of the program in which I am enrolled and outlines procedures for the authorship of articles and presentations related to the findings of this research.

Limitations to the community based participatory nature of this study arose throughout the progression of this research. Such limitations included turnover among community advisors (due to unforeseen events such as illness and relocation) and distance between the researcher and community advisors (generally located in neighbouring provinces). Despite such challenges, it was ensured that a minimum of three community advisors, including at least one youth, were involved in each component of the research process (development, analysis, and planning of dissemination activities).

**Qualitative inquiry.** As noted, a qualitative methodological design was employed in this research. Qualitative approaches to research provide contextual information, offer insight into the meaning of human activities, and are suitable for inductive inquiry (Guba & Lincoln, 1994). Due to the exploratory nature of this study, a qualitative approach was best suited for this research.

As a component of this qualitative inquiry, the research method of photo-voice was employed. Aligned with the principles of community-based participatory research, the photo-voice method is a valuable means of involving youth in the research process, as it encourages youth to identify, represent, and enhance their community (Catalani & Minkler, 2010; Drew, Duncan, & Sawyer, 2010). Generally, photo-voice is employed with three goals in mind, each congruent with community-based participatory research intentions: (1) to enable participants to record and reflect on their community's strengths and concerns; (2) to promote critical dialogue and knowledge about important issues

through large and/or small group discussions of photographs; and (3) to reach policy makers (Wang & Burris, 1997, p.369). In addition to such goals, a fourth objective was put forth in this study: to make use of photographs to inspire oral storytelling, an ancient tradition held within many Aboriginal populations. This tradition is meaningful to the Mi'kmaq community, as it invites and enables listeners to reflect, reconnect, and identify with stories of the past (Hodge, Pasqua, Marquez, & Geishirt-Cantrell, 2002). Further, oral story telling is an ancient tradition within Indigenous inquiry, and has also been incorporated into previous prevention initiatives within the Aboriginal youth population of PEI, initiatives with which members of the community advisory committee have been involved.

The photo-voice methodology has also been used to illicit storytelling in past studies, and particularly within the youth population. The use of photographs in initiating oral accounts has been noted to facilitate in depth interviews and draw on context-rich details that may not otherwise be mentioned. Additionally, this technique may provide youth with a positive, fun perspective toward research, promoting self understanding, communication, and expression (Drew et al., 2010).

Castleden, Garvin, and the Huu-ay-aht First Nation (2008) describe photo-voice as a method which addresses colonialism by challenging such issues as injustice, inequality, and exploitation. Castleden et al., (2008) conducted an evaluation of the photo-voice methodology, wherein content analysis of 45 semi-structured interviews with members of a First Nation located on the West Coast of Canada revealed the methodology's success. In particular, this methodology was found to create a sense of ownership in research, balance power differentials, foster trust, build capacity, and



contribute to the cultural appropriateness of the research process. For example, participants described their independence in determining the subject of their photographs as something which enabled them to set the agenda for the coming interview. This independence thus balanced decision making power between research members, and provided participants with a sense of ownership regarding their community's knowledge. Participants also described the photo-voice methodology to foster trust between research members and to build capacity among participants, as it required an increased level of engagement on behalf of both the researchers and participants. In sum, the photo-voice methodology was found to be a promising means for community-researcher alliances intended to explore important issues while respecting Indigenous perspectives and valuing participants' knowledge (Castleden et al., 2008).

### **Site, Population, Sampling, and Recruitment**

The population invited to participate in this research was the Aboriginal youth community of PEI. PEI is the smallest province of Canada, with an estimated population of 145,855 in 5,660 km<sup>2</sup> (Human Resources Development Canada, 1999; Prince Edward Island Statistics Bureau, 2011). Almost 60% of the population live in rural areas, with only two urban settings in the province (Charlottetown and Summerside). PEI generally maintains a high unemployment rate relative to other provinces, especially those in Western Canada, with workforce numbers fluctuating considerably between months. This is due to seasonal trends in agriculture and fisheries, two of PEI's primary industries (Human Resources Development Canada, 1999).

The population being sampled was the Aboriginal community of PEI, composed of 1,730 individuals. Within this community: 1,230 individuals self-identify as North

American Indian (including Mi'kmaq); 385 self-identify as Métis; 30 self-identify as Inuit; 10 self-identify as having multiple Aboriginal ancestries; and 75 self-identify as an Aboriginal person with ancestry not listed in the above responses. Within this community, approximately 275 individuals are youth within the age bracket of this study (41.8% female and 58.2% male) (Statistics Canada, 2006).

Thirteen Aboriginal youth participated in this study. For the purpose of this research, the term "Aboriginal" encompassed those who self-identified as First Nations, Métis, and/or Inuit. The age range of 16-24 years was chosen in consultation with members of the community advisory committee, as this range was expressed to be a period in the lives of Aboriginal youth during which HIV and HCV risks first arise. To address the literature gap of research involving determinants of risk in rural areas, participants from urban and rural locations participated in separate sessions in order to facilitate a comparative analysis of urban and rural settings. As defined by Statistics Canada (2001), an urban area was considered to be a location with a population of at least 1,000 persons and no fewer than 400 persons per square kilometre.

Participants were recruited using posters describing the study (see Appendix B) which were distributed at various locations in PEI, including offices and events of The Native Council of PEI. While social media was not used as a means for recruitment in this study, snowball sampling was employed to seek additional participants and a representation of both male and female participants. Upon contact from a potential participant, the researcher followed the script outlined in Appendix C, making clarifications in language that was accessible to participants.

## **Data Collection**

Data was collected through a series of sharing sessions which provided a youth-friendly and culturally-comfortable environment. For the purpose of this project, a sharing session was defined as a gathering in which individuals share stories, ideas, suggestions, and opinions for the purposes of self expression, communication, teaching, and learning. Sharing sessions were meant to create a space that reflects the environment and values of Talking Circles, which are gatherings through which Mi'kmaq people practice spirituality through sharing and listening. In Talking Circles, people sit in the form of a circle, with no beginning and no end, and members speak openly concerning issues that may otherwise be private. Talking Circles are sacred and valued within Mi'kmaq culture, being a means of healing and cleansing (Mi'kmaq Association for Cultural Studies, 2013). The sharing sessions of this research project were meant to reflect the respectful, private, comfortable, and safe environment of a Talking Circle.

A sample of six to eight youth was sought for each session to enable peer support to be provided from one group member to another. As a result, sessions were inviting and allowed participants to share information in an unthreatening setting. To circumvent social desirability effects, participants were invited to share stories from the third person (i.e., using "someone I know" as opposed to "I").

Sharing sessions were collaboratively led by the researcher and an Aboriginal youth from the community. The youth discussion leader was reimbursed for their contribution, time, and travel expenses. All sharing sessions were semi-structured, guided using a template of open-ended questions developed in consultation with the community and informed by the literature (See Appendix D). Questions guiding the first sharing

session were broadly structured using Reading and Wien's (2009) *Integrated Life Course and Social Determinants Model of Aboriginal Health*.

Specifically, youth were invited to take part in three interconnected sharing sessions (six sharing sessions took place in total: three sessions with rural participants and three sessions with urban participants). Upon notification of interest, prospective participants had the option of reviewing the process of consent verbally or in written form (see Appendix E). As noted in the process of consent, participation was voluntary and participants were able to leave the study at any point in time. Participants under the age of 18 years were required to seek parental consent, as per the recommendations put forth by the Mi'kmaq Confederacy of PEI Ethics Review Board. Participants were also given an honorarium of fifth-teen dollars for the first session and ten dollars for the second and third sessions in order to thank participants for their time and to cover any costs incurred in travelling to the location of the meetings. Participants were asked to sign a receipt of honorarium to ensure that they had received this reimbursement (see Appendix F).

The first sharing session explored key social determinants of HIV and HCV prevention and risk specific to the Aboriginal youth of PEI. Various determinants, identified from a literature review and from community input, were discussed; however, youth were encouraged to expand this discussion into factors specific to their own historical, social, political, cultural, and economic environments. Upon the conclusion of this discussion, youth were offered a disposable camera with which they were invited to take pictures of factors within their environment(s) that they felt contribute to health promotion and risk prevention for HIV and/or HCV. Such factors could be directly related to risk (such as community areas where youth inject drugs) or indirectly related

(such as cultural events and activities that offer a protective sense of support). Cameras were accompanied by a script, detailing the photo-voice activity (See Appendix G). Once again, participants had the option of reviewing this script orally or in written form. After the script was reviewed, an Aboriginal community member was available for a brief lesson (approximately 30 minutes) on techniques in cultural photography. The community member was reimbursed for his time, and all youth remained at the sessions for this photography lesson.

Following one to three weeks (determined from participant input), the researcher collected cameras from the participants and developed the film. Participants were then invited to reconvene for a second sharing session, in which photos were used to initiate traditional story telling of applicable accounts, events, and environments. A community health worker was available after the second sharing session for youth wishing to debrief. This community worker was available by telephone, in order to respect concerns of confidentiality and anonymity.

Following the first and second sharing sessions, data from these discussions were analysed using thematic network analysis (see next section), and initial findings were informally presented during the third sessions. During this third and final gathering, a discussion surrounding implications toward PEI health promotion and HIV/HCV prevention efforts took place. In taking a strength-based approach, the objective of this final gathering was to provide the participating youth with an overview of all that was discussed in the preceding phases and to verify that this overview appropriately represented the youth's experiences. Additionally, the final sharing session was used to

identify ways in which the stories and information shared in this project can be used in future health promotion and HIV/HCV prevention initiatives.

### **Data Management and Analysis**

All hard copies of consent forms were stored in a secure location until they were transported to a second secure location in Nova Scotia at the Dalhousie University campus. As all sessions were digitally recorded, data from the digital recorder was transferred onto a secure USB flash drive following each session and the digital file on the recorder was erased. The USB flash drive and photos have also been stored at the secure location on the Dalhousie campus. Data from the USB flash drive were transcribed into Atlas.ti verbatim, with no names or identifying information attached to the transcription. The recording on the USB drive was subsequently erased. In effect, there is no way of identifying participants.

Data was transcribed into Atlas.ti, a qualitative data management software package with multiple possibilities for visual data organization. The analysis of the data was guided using thematic network analysis. This method of analysis refers to the “unearthing” of the themes that are salient in a text. This method also refers to facilitating the structuring and depiction of these themes. Specifically, this process involves coding data, identifying themes, constructing thematic networks, and interpreting patterns between and within these networks (Attride-Stirling, 2001). The community advisory committee, including community youth, was involved in verifying codes and themes identified from the data. Thematic network analysis was chosen for this project, as it not only allows for various determinants of HIV/HCV prevention and risk to be identified, but patterns and connections between determinants can also be explored. Photographs

used to illicit storytelling during the second gathering were not analysed, but served to provide discussion points, initiate oral story-telling, and illustrate the findings of that particular session.

During the process of consent, participants had the opportunity to request that they receive a copy of the study's findings. An overview of findings will be provided to all participants requesting this information. Additionally, a copy of the transcripts (with identifying information removed) and a formal copy of the final thesis report, including analysis of data, will be provided to the community advisory committee before thesis defense.

### **Rigor of Data**

Ensuring the trustworthiness of qualitative data involves the establishment of credibility, transferability, and dependability (Graneheim & Lundman, 2003). First, credibility involves three related elements of inquiry, each contributing to the meaningful representation of participant experiences: 1) rigorous technique for gathering and analyzing data; 2) the credibility of the researcher; and 3) the philosophical approach of the qualitative inquiry. In order to assure the highest credibility of findings, several actions have been taken. For instance, a "member checking" activity took place during the third sharing session, wherein participants were invited to comment on the initial analysis outcomes. Participants were also asked to verify the accuracy of such outcomes according to their experiences. Additional actions to ensure the credibility of data include the transparent reporting of methodology in dissemination work as well as analyst triangulation (using more than one analyst to review findings), in which the community advisory committee and academic supervisor were involved (Patton, 1999).

The second means of establishing trustworthiness of data is through ensuring transferability. The current study seeks to identify social determinants of risk and prevention within a specific province, population, and age frame; therefore, results are not intended to transfer to the general public. However, the methodology of this study will be reported transparently and thoroughly to enable the replication of this study in other provinces and contexts.

The final element in establishing trustworthiness of data is dependability, which addresses the researcher's influence on the process of data analysis and interpretation. Transparency in methodological processes will once again aid in ensuring the dependability of data, with sampling procedures, data collection, and analysis to be outlined in depth in research reports. Additionally, I have adapted a reflexive approach as a researcher. This involves acknowledging the ways in which my assumptions, values, experiences, and culture interact with the research process and, importantly, with the community with whom I am working.

### **Knowledge Transfer**

Preliminary research findings were presented to all participants during the final sharing sessions of this study. Additionally, all findings were made available to the community advisory committee and discussions with the community advisory committee continued during preparation for the thesis defence to determine next steps for knowledge translation (i.e., presentations, info-cards to be distributed to Aboriginal youth across PEI). It is important that the community has ownership of the study's findings, and that possible means for incorporating findings into prevention policy and programming be discussed. Indeed, the community's ownership and control throughout the research



project, access to data, possession of findings, and the community's involvement in knowledge transfer, are central to research with Aboriginal peoples and are essential to the community-based research process (see next section) (Minkler & Wallerstein, 2003; Schnarch, 2004).

Academic dissemination of results will involve the submission of findings to a peer-reviewed journal as well as presentations of findings at provincial and national levels.

### **Ethical Considerations**

The current project begs several ethical considerations, many of which are specified by chapter nine of the Tri-Council Policy Statement on the Ethical Conduct of Research Involving Humans, which specifically details ethical expectations for research involving Aboriginal Peoples (Canadian Institute of Health Research, 2010). The following section describes the ways in which this project addresses various ethical considerations, including: informed consent; privacy, confidentiality, and anonymity; potential harm; and the OCAP™ principles.

**Informed consent.** Before data collection began, free and informed consent was obtained from all participants. Participants under the age of 18 years were required to seek parental consent, as per the recommendations put forth by the Mi'kmaq Confederacy of PEI Ethics Review Board. Participants had the option of reviewing the process of consent in oral or written form, as literacy skills were not a prerequisite for participation in this study. Additionally, the process of oral consent is aligned with the oral traditions of Mi'kmaq peoples.

The process of consent outlined the study's purpose, potential discussion questions, and potential risks and benefits. Participants were also assured that their participation in the study was voluntary, and that they could leave the study at any point without penalty or question. Participants were informed that participation was confidential, meaning all names, locations, and identifying information was removed from transcripts. Before offering consent, participants were asked if they had any additional questions regarding the research, or their role in the research project. Finally, participants were asked to complete a very brief demographic information form (see Appendix H). Once again, participants were reassured that no identifying information would be included in any final posters, reports, or presentations. Participants were invited to indicate (on page 2 of the demographic questionnaire) whether they would like to be identified and recognized for their contributions in this study.

**Privacy and confidentiality.** All sharing sessions were conducted in a private location chosen in consultation with the community and participating youth in order to moderate any concerns regarding privacy of group meetings. Participants were also assured that all responses would be kept confidential, apart from only three circumstances in which confidentiality would not be maintained: 1) if the participant was in a situation of harm or abuse from another individual; 2) if the participant was in danger of self-harm; or 3) if the participant indicated the abuse of an adult or child in need of protection. In such cases, this information would be passed on to the appropriate community worker. Anonymity was not entirely possible with the nature of this research; however, all measures were taken to ensure that participants were not identified to others.

All information was stored in a secure office at Stairs House, Dalhousie University, and in a password protected USB for a period of 5 years after publication, at which time the information will be destroyed. Materials containing names, such as consent forms, were kept separate from transcripts.

**Potential harm.** Topics that were discussed during the gatherings, such as HIV and IDU, are sensitive topics of discussion. It was therefore possible that participants might become emotionally or psychologically upset or uncomfortable as a result of participating. Participants were assured that they were not required to answer all questions and participants were welcomed to take a break, or end participation, at any time during the discussion. Participants were also offered a listing of information sources (such as the Kids' Help Line and various community resources) prior to each session, which detailed sexual health and drug support services in PEI (see Appendix I).

There were no direct benefits to participating in this study; however, it is possible that participants experienced positive feelings from engaging in interactive discussions with peers. It is also possible that participants learned about HIV/HCV prevention information from one another's stories and/or ideas, or learned photographic techniques from the photography lesson offered at the end of the first sharing session. Moreover, youth participating in this study may have felt empowered to participate within the community in health promotion or prevention initiatives, and may have benefited others by creating new knowledge surrounding HIV and HCV prevention and risk among Aboriginal youth in PEI.

**The OCAP<sup>TM</sup> principles.** According to Schnarch (2004), the principles of ownership, control, access, and possession (OCAP<sup>TM</sup>) embody self-determination applied

to research with First Nations peoples. The OCAP<sup>TM</sup> principles are altering the ways in which researchers work with Aboriginal communities, and are principles which were incorporated into this study.

The first principle, being ownership, refers to the relationship between First Nations communities and their cultural knowledge, information, and data. The second, being control, refers to the rights of First Nations communities to maintain and re-establish control over all aspects of life, including research involvement. Further, First Nations communities must have both access to and possession of information about themselves and their communities. In order to apply the OCAP<sup>TM</sup> principles in practice, it is essential that First Nations communities be recognized as having jurisdiction over research activity within their communities (Schnarch, 2004).

The principles of ownership, control, access, and possession are specified within the research collaboration agreement between the research advisory committee of this study and myself, the researcher. Specifically, this agreement acknowledges Aboriginal peoples' ownership of the knowledge, information, and data collected in this research study. The agreement further specifies that the Aboriginal peoples of PEI have control over all involvement in this project, and that community advisors have access to and possession of data transcripts (trimmed of identifying information), photos, and findings obtained in this study. Moreover, the community will have access to and possession of proposal and thesis reports submitted to Dalhousie University.

**Additional ethical considerations.** Additional ethical considerations involve the sensitive nature of the study's focus, respect for Aboriginal worldviews, community involvement and capacity building, mutual participation in the interpretation and

dissemination of results, and mutual benefit (Canadian Institute of Health Research, 2010). Such ethical concerns are addressed through various components of this study, including: the involvement of Aboriginal youth in the research process; partnership with the community advisory committee; the incorporation of oral story telling; and the involvement of participants in the interpretation and dissemination of results.

This study was approved by the Dalhousie University Health Sciences Research Ethics Board, the Mi'kmaw Ethics Watch, and the Mi'kmaq Confederacy of PEI Ethics Review Board.

### **Study Limitations**

As with any research project, limitations exist within this study. A first limitation of this research can be found in the potential bias of the participant group of youth who took part in this research. For instance, youth who offered consent to this study are potentially youth who have been active in prevention programming in the past; therefore, youth whose voices have yet to be heard may not have been available to participate in this project. In order to moderate this limitation, recruitment posters were friendly to low literacy levels, and posters were distributed at diverse locations.

As noted, limitations also challenged the community-based approach of this study. For example, the nature of the Master's program in which I am enrolled challenged the equitable involvement of community members in all components of the research project, as I (as a student) am independently responsible for the writing and presentation of proposal and thesis material. This limitation is recognized in the principles of research collaboration agreement. Additionally, my status as a non-Aboriginal youth, studying the first-voice experiences of Aboriginal youth, posed challenges in meaningfully

representing the voices of Aboriginal youth of PEI. With the active involvement of the community advisory committee, the meaningful engagement of participants, and my shared experiences as a youth of PEI, it is hoped that the voices of Aboriginal youth of PEI have been respectfully represented.

The scope and time allotted for the Master's program in which I am enrolled also posed limitations on this project. For instance, a significant period of this two-year program was allotted to completing coursework required for the Master's program and seeking ethical approval from academic and community ethics boards. Time allotted to preparing the final thesis document and planning dissemination activities was limited.

A final limitation of this study lies in the use of the term Aboriginal as a representation of the youth who participated in this research. Although First Nations, Inuit, and Métis youth were invited to participate, the demographic questionnaire distributed to participants did not ask youth to identify their specific community (First Nations, Inuit, or Métis). Therefore, while it cannot be certain that youth of each First Nations, Inuit, and Métis communities took part, the term Aboriginal is used in this project to ensure the inclusion of each community invited to participate.

### **Summary of Chapter 3**

This chapter reviewed the theoretical orientations and methodological approach that guided this study. Further, this chapter discussed my identity and reflexivity as a researcher, as well as research methodology, knowledge transfer, ethical considerations, and study limitations. The following chapter will review findings yielded from the analysis of data.

## **Chapter 4: Findings**

This chapter will provide an overview of participant demographics and will detail the findings from this investigation in relation to the key research questions. More specifically, this chapter will describe core themes, subthemes, and the primary thematic network which arose from the analysis of the data by means of thematic network analysis. Themes will be illustrated using both direct quotations and photographs taken by the youth participants. In addition, differences within and among emergent themes and subthemes will be explored with regard to geographic location, and implications toward the discipline of health promotion will be reviewed.

Several themes identified from the data show congruency with Reading and Wien's *Integrated Life Course and Social Determinants Model of Aboriginal Health*. As such, themes will be presented within the context of proximal, intermediate, and distal determinants of health with particular attention being paid to the interacting nature of the themes in addition to their life-course characteristics. This chapter will first present themes relevant to proximal determinants of HIV/HCV prevention and risk, followed by themes relevant to intermediate determinants, and finally themes relevant to distal determinants. Emergent subthemes will also be reviewed, as indicated by the use of subheadings. Finally, a model for the key determinants of HIV/HCV prevention and risk among Aboriginal youth of PEI will be presented.

### **Sample Demographics**

Before discussing core emergent themes, it is necessary to review the participant demographics of this study, which included a total of 13 participating youth. In accordance with the inclusion criterion, all participants self-identified as Aboriginal

(Métis, Inuit, and/or First Nations), were between the ages of 16 and 24 years, and lived in PEI for at least one year between the ages of 16 and 24.

Six participants took part in the urban sharing sessions while seven participants took part in the rural sharing sessions. Of the six participants who took part in the urban sharing sessions, all lived off-reserve in the city of Charlottetown. Two of the six participants were male and four were female. The average age of participants taking part in the urban sessions was 18.5 years and participants had completed an average of 11.2 years of education. Of the seven participants who took part in the rural sharing sessions, six participants reported living on reserve and one participant reported living off reserve in a local town. Two of the seven participants were male and five were female. The average age of the participants taking part in the rural sessions was 20.3 years and participants had completed an average of 12 years of education.

### **Understandings of HIV/HCV Prevention and Risk**

At the beginning of the first urban and rural sharing sessions, participants were asked, “what does HIV and Hepatitis C prevention mean to you?” in addition to, “What does HIV and Hepatitis C risk mean to you?”. These questions were asked in order to establish a shared understanding of HIV and HCV prevention and risk among participants before continuing with the sessions. The following section details two core themes emerging from participants’ conceptual understandings of HIV and HCV, being participants’ understandings of prevention and participants’ understandings of risk. Such themes emerged in a consistent way across urban, rural, male, and female participant groups.



**Prevention.** Participants understood HIV and HCV prevention as the act of being informed, aware, trained, and involved in all aspects of prevention, such as reducing harms. Being informed and aware of HIV and HCV related issues was central to participants' understandings of prevention, both among urban and rural participants. When asked the meaning of prevention, a participant from the rural session replied with, "*To be educated*" (Female participant, rural sharing session #1). Similarly, a participant from the urban session answered, "*Being involved and being aware and being trained in every aspect of HIV/AIDS*" (Female participant, urban sharing session #1). The importance of information and education was very much a key element of participants' understandings of prevention, and is an important element which will be revisited within this chapter.

Specific topics relevant to participants' understandings of HIV and HCV prevention largely involved reducing harms associated with sex, rather than needle use or other activities. Several participants expressed confidence in having control over preventing such harms, for example by being prepared and carrying a condom. A participant from the rural sharing session expressed the meaning of prevention as, "*You should always know to be prepared, always have condoms*" (Female participant, rural sharing session #1) and, "*safe sex*" (Female participant, rural sharing session #1). Although participants viewed harms associated with sex as preventable, harms associated with needle use were viewed to be less so, contributing to participants' understandings of risk.

**Risk.** A second core theme emerging from the analysis included participants' understandings of HIV and HCV risk. Understandings of risk encompassed feelings of

vulnerability to infection in addition to perceptions of what being HIV or HCV positive might be like. Both urban and rural participants' perceived vulnerability to infection was heavily related to IDU; as noted, participants expressed feeling in control with respect to sex related harms but then expressed feeling vulnerable toward IDU related harms. For example, some participants understood injection drug users to be potentially unsafe or dangerous, expressing feelings of vulnerability when in an environment where IDU is present. As one participant shared,

*I think I would be more scared of catching it from doing drugs than having sex, like you know the person you're having sex with, obviously you're not gonna be too worried about that. It's just like junkies, you don't know what junkies are gonna do to you. Or like you hear about people robbing places with needles (Female participant, rural sharing session #1).*

A second participant added to this, discussing her fear of needles in the environment,

*The crazy thing is, like people put needles in things. In California just last week a couple of days ago people were getting pricked by needles that were placed in gas pumps and getting HIV from them. Yeah, so like you can be safe all you want but crazy shit like that, how do you avoid that? People pump gas all day every day. That's scary (Female participant, rural sharing session #1).*

Although this last quote shares a media story which was in fact untrue, this quote speaks to youth's feelings of vulnerability toward the presence of needles in the environment, and also highlights the influence which media carries on the risk perceptions of youth. Indeed, feelings of vulnerability toward needles within the environment and injection

drug users were key components held within participants' understandings of risk to HIV and HCV infection.

Youth's understandings of risk also involved perceptions of what being HIV or HCV positive might be like. Specific perceptions of HIV/HCV positivity relating to risk included depression, isolation, sickness, and death. When asked the meaning of HIV and/or HCV risk, three participants from the rural sharing session answered with "*death*" while one participant added "*sickness*". Participants also commented on the experiences one might have when living with HIV and/or HCV, including experiences of social exclusion from family and friends. For example, a participant from the rural sharing session discussed feeling isolated while a participant from the urban session shared, "*To me it just makes it sound like you're different, you're infected*" (Female participant, urban sharing session #1). This last quotation introduces the notion of stigma surrounding HIV and HCV, a notion which will be revisited later in this chapter.

### **Proximal Determinants of HIV and HCV Prevention and Risk**

As noted, the majority of core themes emerging from the thematic analysis of the data coincide with Reading and Wien's *Integrated Life Course and Social Determinants Model of Aboriginal Health*. These core themes, along with their corresponding subthemes, are detailed below, beginning with proximal determinants of HIV and HCV prevention and risk. This discussion now includes findings from the data and insights of all six sessions, while the previous section spoke only to an early discussion of the first urban and rural sharing sessions.

**Contexts of prevention and risk.** Environmental contexts emerged as a core theme and a determinant of prevention and risk to HIV/HCV. That is, the youth participating in this study spoke of specific contexts experienced by Aboriginal young people living in rural and urban PEI. Such contexts encompassed social environments which contribute to HIV/HCV prevention and risk, in addition to physical environmental factors, namely needles, related to risk. According to Reading and Wien's *Integrated Life Course and Social Determinants Model of Aboriginal Health*, contexts within one's immediate environment are considered to be proximal determinants of health. Therefore, the following discussion explores proximal determinants of HIV/HCV prevention and risk, identified by Aboriginal youth of PEI.

***Social environment.*** As a subtheme of environmental contexts of prevention and risk, participants identified factors specifically within their social environment that affect prevention and risk to HIV and HCV. For example, a sense of community togetherness was discussed as an avenue for interpersonal support and prevention of substance use. A second example involved the presence of HIV, AIDS, HCV, and IDU within the community, which created a context for prevention and awareness, while also creating a context for risk. As such, community togetherness, along with the presence of HIV, AIDS, HCV and IDU, were identified to be key proximal determinants of HIV/HCV prevention and risk.

A sense of community togetherness was a very clear means of prevention among the participants of this study. The meaning of community togetherness was expressed as an influential presence of support, friendship, and commitment among community

members, including family members and peers. As one participant shared, *“I took a picture of hands holding each other, because friends give us support, you know what I mean? Before when I was upset, friends help out”* (Female Participant, rural sharing session #2, see figure 1). A second participant shared,

*Well the picture that I took of the teepee, I laid on the ground and took a picture up at the teepee. Like when you look up at it you can see that like every, every pole was leaning on one another for like support. It’s like the community for each other against addiction, maybe* (Female Participant, rural Sharing Session #2, see figure 2).

Community togetherness was viewed to be a key preventative measure, particularly with regard to substance use and addiction, on both individual and community levels. For example, support offered by community members, family, and friends was noted as especially helpful when youth were experiencing difficult times or when youth might be considering substance use. This community togetherness was also noted as beneficial to the community as a whole, representing a unified voice against the harms of addiction.



*Figure 1.* Participants’ photographs illustrating community togetherness



*Figure 2.* Participant's photographs representing community support toward addiction prevention

The discussion of issues related to substance use, addiction, and IDU was comprehensive, and was present during each of the six sharing sessions. This was perhaps related to participants' conceptualization of risk in addition to participants' experiences with IDU, HIV, AIDS, and HCV within the community. Indeed, the presence of IDU, HIV, AIDS, and HCV within participants' communities seemingly shaped participants' interest in prevention initiatives. For instance, this presence provided participants with an appreciation of the importance of prevention and also provided participants with information related to key HIV/HCV prevention issues. Several participants, in both urban and rural sharing sessions, spoke of their experiences encountering individuals using injection drugs. A participant in the rural session shared a story about a friend who was exposed to HCV through IDU, "*Well I know someone who caught Hepatitis from sharing the same water with their needles. Yeah, just the same, taking their needles..*" (Female participant, rural sharing session #1). A second participant continued,

*The same spoon. She caught it that way and didn't even realize that she could contract that. I think she was pregnant and she found out whenever she went to the doctor that she had Hepatitis and she was confused as to how she got it, and it was because she was sharing the spoon. She shared the spoon and then she had it.” (Female participant, rural sharing session #1).*

Through this story, we see that the participant knew a woman who contracted HCV through IDU and as a result of this experience, the participant gained awareness and information regarding means of HIV/HCV transmission and detection. Additional stories, similar to that included above, illustrate that the presence of IDU, HIV, AIDS, and HCV within participants' urban and rural environments create a context for prevention. As noted, this context is created through the spreading of both awareness and information.

Experiences with individuals using substances more broadly may also shape youth's views toward addiction prevention. For instance, some participants shared concerns that the use of one drug might lead to the use of another, *“Even if you think to yourself, well if I just smoke one puff of a cigarette it's not going to harm you than you just smoke more and more and it's the same with weed or anything”* (Female participant, urban Sharing Session #2, see figure 3). A second participant included,

*I guess the big thing would be like intravenous drugs and just like one drug always leads to another, right? One drug always leads to another and at some point it's going to lead to intravenous drugs, right? Not always, but in a lot of cases it does* (Female participant, urban sharing session #1).

From this discussion, we can see that many participants expressed strong feelings toward the importance of preventing substance use. Because participants viewed all substances to

be very connected, this prevention is applicable to smoking, alcohol use, and marijuana use, in addition to the prevention of IDU.



*Figure 3.* Participants' photographs of cigarettes as an illustration of what might lead to additional substance use

Indeed, the presence of substance use, IDU, HIV, AIDS, and HCV within participants' environments created a context for prevention by means of spreading awareness and information; however, participants living in rural areas also viewed this presence to create a context for risk. For instance, some participants spoke of their time involved with the correctional system where they felt particularly vulnerable to HIV/HCV exposure as a result of knowing others who were HIV or HCV positive. As a participant from the rural session explained,

*Because I was in jail before and there was a lot of girls who had HIV and Hepatitis C and (...) They walk around like it's nothing, you know what I mean? And you're like there and you're unprotected because you're already in jail with them (Female participant, rural sharing session #1).*



In this way, the presence of IDU, HIV, and HCV within participants' immediate environment also created a perceived context for risk, as participants felt more vulnerable to infection. This physical risk is discussed in greater depth in the following section.

***Physical environment.*** The physical environment is a second subtheme emerging from the discussion of contexts of prevention and risk. That is, in addition to the social environmental context, the physical environmental context was also noted to influence prevention and risk to HIV/HCV.

The overarching theme surrounding risk within the physical environment was overwhelmingly related to the presence of needles. This subtheme emerged very clearly among both urban and rural participant groups, as participants discussed their experiences finding needles in parks, parking lots, bars, bathrooms (i.e., at a local gas station or food venue), and on sidewalks. As one participant expressed, "*You find a lot of needles around PEI, like anywhere, at kid's parks, playgrounds, schools*" (Female participant, urban sharing session #1). Another participant shared a story expressing his concern over finding needles in his car after a youth activity,

*Recently we went on a trip to [local outdoor activity location] and we had six people in my car and every Saturday I usually clean my car, shine it all up, take it to the car wash and I found this black bag in my vehicle and I had no idea what it was and my mother asked me what it was and I said, oh I dunno what it is don't worry about it. It's probably one of the kid's, I'll drop it off when I get home. So when I dropped my parents off to their appointment then afterward we went to [local venue] and my mom looked inside the bag and it was needles. Oh boy was I pissed. I was kind of mad because it was a slap in the face for me because ok*

*we're going on a youth event trying to prevent that stuff* (Male participant, rural sharing session #1).

Participants expressed concern that community members may become injured or infected if they come in contact with needles present within the environment. It was also expressed that needles pose risks to those across the entire life course, as needles had been found near parks and playgrounds used by children. This may differ from the presence of IDU, HIV, AIDS, and HCV, as this presence is in some ways less visible to the younger community (i.e., below the adolescent years). Figure 4 displays photographs taken by participants to illustrate areas where they experienced the presence of needles.



*Figure 4.* Participants' photographs of areas where needles had been encountered

The presence of physical risk was described to differ by rurality, neighborhood, and location. Within the urban sessions, discussion surrounded neighborhoods of lower income or increased disadvantage, where it is more common to find needles. There was also a discussion surrounding various “types” of bars, where some bars might pose greater risks than others. Perhaps due to this location-specific nature of risk, participants' experiences finding needles were diverse; for example, one participant noted, *“The only encounter I had with needles was with the vaccination at the wellness center”* (Female

participant, rural sharing session #1). This inconsistency across the physical environment illustrates the importance of place within the discussion of health promotion, and specifically within the discussion of physical risk and HIV/HCV prevention.

**Information.** An additional core theme which emerged from the thematic analysis of the data involved access to HIV and HCV related information. Given that participants conceptualized the prevention of HIV and HCV as involving knowledge and information, access to this information was indeed a central topic of discussion. Participants accessed information within their immediate environments and thus, access to information is considered an additional proximal determinant of HIV/HCV prevention.

Participants accessed information about HIV and HCV from a variety of sources, including: family, peers, media, cultural groups, community groups, community workers, presentations, and workshops. Although presentations and workshops were discussed in brief, participants largely accessed information about HIV and HCV in ways which were more interactive and involved. For instance, several participants discussed accessing information through their relationships with family, friends, and community contacts who they had met through cultural groups or community programs (see figure 5). As one participant shared, “*Well I can talk to my mom about it [HIV and HCV] like any day. I just ask a question and we can have a whole conversation*” (Female participant, rural sharing session #1). Youth living in urban areas of the province discussed their experiences gaining knowledge about HIV and HCV from community workers with a Hepatitis C program for Aboriginal youth. One participant shared, “*I just tell her [community member/worker] about stuff on the Pow-Wow trails and she tells me, ‘make sure you’re safe, make sure you use condoms, always take precautions’*” (Male

participant, urban sharing session #1). A second participant discussed her experiences with HCV programming, *“It teaches us what to look out for and what to not, you know what I mean? It helps you identify things, to know if you have anything, to know what it is”* (Female participant, urban sharing session #1). Because health programming is more generally housed within urban locations, rural youth spoke less of their experiences gaining information from community contacts and talked more about gaining awareness and information through experiential learning (i.e., through experiences with IDU, HCV, HIV, or AIDS, as previously discussed).



*Figure 5.* Photographs taken by participants representing points of access to HIV and HCV related information (family, community)

An additional point of access to HIV and HCV related information among urban youth was through experiences of travel and migration. The urban youth participating in this research spoke of their time traveling to and/or moving from Vancouver, Toronto, Nova Scotia, New Brunswick, and the United States, where they encountered various HCV/HIV prevention and risk experiences. For example, some participants spoke about their experiences encountering needles when living or travelling in Toronto and East

Vancouver. Other participants discussed gaining prevention related information in Nova Scotia and New Brunswick. As one participant shared,

*When I went to junior high it was in [out of province city], that's where I practically grew up, and like our junior high had condom machines and tampon machines together. I think they should bring those back because that's a really good idea, if a girl walks in and she's thinking about having sex she can be like, a condom, I need one of those. Then you're always prepared (Female participant, urban sharing session #2).*

A second participant shared her experiences from time spent out of province,

*I know there was this thing I think it was [out of province AIDS service organization]. We went there with [community member/worker] just for a visit to see how their facility works and it was really cool because like they had everything. It was really nice and it was really clean and they had a front door and a back door so it was just like a normal house but it was their office. And as we were in there the girl there was talking to us about everything and a client of hers came in with dirty needles and she like exchanged them and gave out a care pack that had like clean needles, a disposal bin, alcohol swabs, cotton balls, and everything in it, like it was really cool (Female participant, urban sharing session #1)*

Thus, participants living in urban areas also gained awareness and information concerning HIV/HCV prevention and risk from both travel and migration experiences. Information gained from these experiences involved risk factors in addition to means of

prevention and reducing harms, such as condom machines and needles exchange services.

Interestingly, participants also talked about accessing information from the sharing sessions themselves. Participants used the time spent with the facilitator and the researcher as an opportunity to ask HIV and HCV related questions. As such, participants related the sharing sessions to prevention workshops and community programs. When asking questions, topics of interest were diverse; for example, participants posed questions relating to HIV/HCV basics, prevention, transmission, detection, and diversity. Questions asked by participants included: “*And so HIV, what does that affect and does that lead to AIDS?*” (Male participant, rural sharing session #1); “*Can you get it [HIV] from just having unprotected sex with somebody the same person all the time? Like, or does that person have to have that disease for me to get that?*” (Female participant, rural sharing session #1); “*How would you know if you had it [HCV]?*” (Male participant, rural sharing session #1); “*So HIV is that, does that come from, from I don’t know the right term, but gay people? Would that be more of a factor for them?*” (Male participant, rural sharing session #1). Of note, most questions were asked from youth living in rural areas, which may represent a lack of available and/or accessible information to youth living outside of urban settings.

### **Intermediate Determinants of HIV and HCV Prevention and Risk**

Access to information concludes the discussion of themes relating to proximal determinants of health. Thus, the next section of this chapter will review those themes relevant to intermediate determinants of HIV and HCV prevention and risk.

**Systems.** An additional core theme which emerged from the thematic analysis of the data is the theme of systems (i.e., health systems, educational systems) within youth's environments that influence HIV and HCV prevention and risk. According to the *Integrated Life Course and Social Determinants Model of Aboriginal Health*, systems within one's environment are considered to be intermediate determinants of health and well-being. Subthemes corresponding to this core theme include: sexual health services; the school system; and community programming.

**Sexual health services.** Participants discussed various sexual health services available within their environment, such as condom distribution and HIV/HCV testing. Condoms were readily accessed by participants through local health centers, community organizations, and the provincial AIDS Service Organization (ASO). One participant spoke of the reserve health center, "*They have yellow ones, black ones, blue ones [condoms]. Yeah I go up to the health center and take them all*" (Female participant, rural sharing session #1, see figure 6). Another participant shared, "*This is my picture of the health center. We can get condoms and information there and we go to youth group at the health center*" (Female participant, rural sharing session #2, see figure 6). Thus, youth frequently accessed condom distribution services available within both urban and rural settings.



*Figure 6.* Photographs taken by participants illustrating access to sexual health services (condom distribution, community health center)

While condoms were readily accessed by participants, testing services for sexually transmitted infections were accessed to a lesser extent. However, two participants did share their stories about being tested for HIV. Such stories encompassed fear of testing positive, stigma surrounding being tested for “AIDS”, and anxiety arising between the time of testing and the time when results are shared with the patient. As one youth described,

*And it was the scariest, like the scariest. You're up at night and you're just like oh my God like what if, what if. And it was like oh, thank God. It was the scariest thing in the world to be sitting there waiting for an AIDS test. (Female participant, rural sharing session #1).*

Although experiences of testing were not described by participants as being particularly positive, participants did express satisfaction with the availability and accessibility of these services. Participants who had received testing did not specify where they had accessed the service, however participants who were not previously tested said, if they



were to access testing services, they would approach their family physician or provincial ASO.

***School system.*** While participants were generally satisfied with availability and accessibility of sexual health services in the community, participants did not express this same satisfaction when discussing HIV/HCV related issues within the school system. For example, participants experienced a lack of prevention education at school, relating directly to the theme of information, as previously discussed. Participants also discussed experiences of bullying, racial discrimination, and social exclusion (see figure 7).

Participants shared various pieces of information which were learned from experiences in the school system. However, the majority of such information was related to sexual development and sexual maturity. As one participant shared, *“In sex and health class they don’t really talk about AIDS or Hepatitis or anything like that, they talk mostly about your period and puberty and everything”* (Female participant, urban sharing session #1). While participants generally expressed their school education to have decreased their risk to HIV and HCV, participants also expressed a need for the provision of additional information. That is, youth suggested that information surrounding sexually transmitted infections and safer sex be discussed in much greater detail, and with an emphasis on practical application of the information (i.e., how to use a condom).



*Figure 7.* Photographs taken by participants representing experiences within the school system

Participants also discussed the environment of a public school classroom. For instance, some youth discussed the attitudes held by students surrounding issues relevant to HIV and HCV. Such attitudes created an environment where youth were hesitant to ask questions in the classroom and therefore youth may have missed key prevention information. As participants were discussing whether the school system provided sufficient HIV/HCV prevention information, one participant responded, *“Not in school I wouldn’t say, because it was awkward, like I didn’t want to talk about it in school because your friends are all there and they’re laughing and giggling”* (Female participant, rural sharing session #1). This suggests the importance of safe spaces within the classroom where youth can ask difficult questions, for example those pertaining to HIV or HCV.

Additionally, youth participating in this study shared experiences of racial discrimination and social exclusion. Although it was not clear whether these experiences were related (i.e., whether social exclusion was a function of racial discrimination), participants noted that both issues posed reason for concern, specifically within urban

settings of the province. Social exclusion experienced within urban schools would lead to lateral violence, where the student experiencing exclusion would direct their dissatisfaction toward others. In turn, the student experiencing social exclusion would be reprimanded by suspension or another form of discipline, wherein students would often miss valuable educational material and potentially material relevant to sexual health and substance use prevention. One youth discussed his experiences with lateral violence, suggesting the importance of building awareness among teachers surrounding needs and culture of Aboriginal students:

*And they [teachers] should be told that there actually are Native kids that go to their school. Kids would try to fight me and I'd get so mad that I'd fight them. I'd let them hit me first so I wouldn't get in trouble and then I'd stick up for myself and beat them up and I'd get suspended for it (Male participant, urban sharing session #1).*

A second youth participant discussed her experiences being treated differently from non-Aboriginal students. This was perhaps due to stigmatizing attitudes directed toward race. In discussing the presence of racial discrimination and bullying within the school, the participant shared,

*Especially against the Native students. I used to go to that school and I literally had to drop out of school and I was getting bullied so bad it got to the point where I got burned on my arm because they didn't like Natives (Female participant, urban sharing session #2).*

As seen, participants shared stories which tell of experiences surrounding school related stigma, racial discrimination, and social exclusion.

**Community programming.** Identified by the participants of this study, community programming is an additional system-level, intermediate determinant of HIV/HCV prevention and risk. Community programming is related to both community togetherness and access to information, but also provides additional insight into HIV/HCV prevention and risk (see figure 8).



*Figure 8.* A participant's photograph illustrating community programming

Participants identified community programs as a means for being involved within the community, which was related to participants' conceptualization of HIV/HCV prevention. Additionally, participants identified community programming as an avenue that interactively connects participants to information, events, peers, community members, and mentors. Notably, participants discussed receiving *and* sharing information at events and with peers, community members, and mentors. One participant shared her experience learning from a community program worker and then sharing this information with peers,

*I actually did that before, since grade 8 when I first started the group with [community member/worker] and everyone would come up to me and ask for*

*condoms. And they would sit there and talk with me at lunch time and ask me questions and like whatever I couldn't answer I would ask [community member/worker] and get back to them the next day. And it was just cool that people came to me to ask questions. I could just help them and give them answers* (Female participant, urban sharing session #1).

As seen from this quote, the sharing of information was a key success yielded by community programs. Additional successes included participants' built connections with peers, community members, and mentors. Stories relating to the successes of community programming were generally shared by the youth participating in the urban sharing sessions, again because the majority of HIV/HCV related programming occurs within the province's central urban location.

While community programming has successfully provided education, experiences, and mentorship to participants who took part in the urban sessions, participating youth also identified a need for continuity and sustainability within these programs. For example, youth discussed staff turnover within community programs, which was related to changes in the consistency of program gatherings. One participant expressed, "*Well after [community member/worker] left we lost all of our connections to those things or anything like that [prevention activities]*" (Female participant, urban sharing session #1). Further, participants shared positive feelings toward a past community worker, but also shared their feelings of missing this worker and the program itself, "*It's just hard to go from talking about it [Hepatitis C prevention] every day and messaging our coordinator every day to not doing anything, like there's nothing really now* (Female participant, urban sharing session #1). Thus, youth suggested the

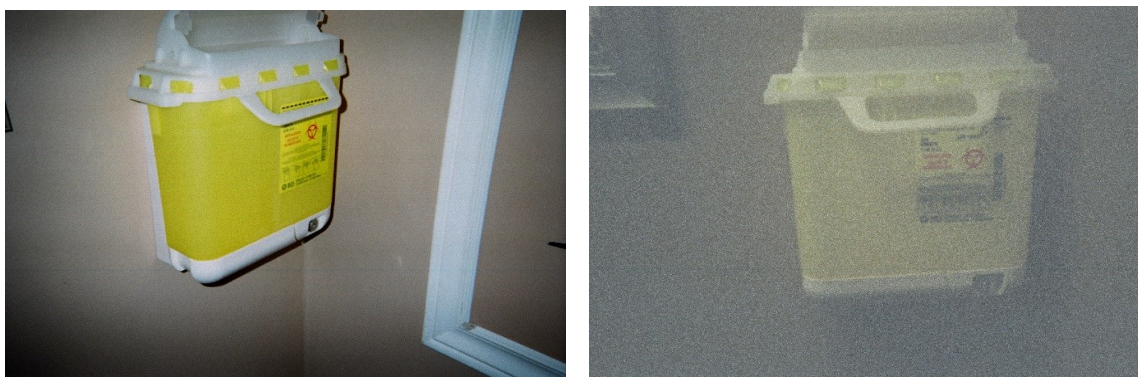
importance of program sustainability and a continuation of built connections. Further, given that discussion surrounding community programs occurred almost entirely among participants of urban PEI, it is important that HIV and HCV prevention programs involve young people living in both urban and rural areas.

Youth discussed various activities and topics explored within prevention programs, and many of these involved the notion of reducing harms. Participants also discussed the reduction of harms within the context of other environmental systems (i.e., health, school), and therefore the reduction of harms is an additional intermediate determinant of HIV and HCV prevention and risk.

**Reducing harms.** The reduction of harms is a core theme which emerged from the thematic analysis of the data, being the second core theme relevant to intermediate determinants of HIV and HCV prevention and risk. Youth participating in this study explored ways by which health centers, schools, and the broader community might improve efforts to reduce harms. Many of these ideas, and particularly those shared from urban sessions, stemmed from lessons learned from community programs. Such ideas and discussions surrounded reducing harms relating to IDU, sex, and tattooing.

Several participants in both rural and urban sharing sessions emphasized the importance of keeping the physical environment needle-free in order to reduce potential harms associated with IDU. Youth first discussed the importance of having someone to contact if one were to encounter a needle on the sidewalk, at school, a bar, or another location. Subsequently, participants discussed increasing the presence of needle disposals in the province. One participant shared, *“I think people should go in and talk to store owners to see if they can put them [needle disposal bins] in their stores, and maybe talk*

to government” (Female participant, urban sharing session #2). A second participant responded, “*If I had one of those yellow bins I’d go in and I’d drill it to the wall there [local venue] myself*” (Female participant, urban sharing session #2). Responding to the presence of needles within the physical environment (as discussed in previous themes), participants recognized increasing the availability of needle disposal bins as a key means for reducing IDU related harms (see figure 9). The connection between the reduction of harms and the physical environment links the intermediate determinants of reducing harms to the proximal determinants of health previously explored.



*Figure 9.* Participants’ photographs representing the reduction of potential harms related to IDU

Participants identified an additional means for reducing IDU related harms, which involved increasing the availability of needle exchange locations and establishing a safe injection site. Urban participants discussed learning about needle exchange sites and safe injection sites through travel and migration, and also through HCV prevention programs. After sharing information gained from these sources, youth offered various ideas regarding both needle exchange and safe injection locations. As one participant shared, “*I just want to have a place like [out of province needle exchange service], just a place that*

*people know of where people can come in and get their stuff. And there could be a basement where youth could come in every week”* (Female participant, urban sharing session #1). Here, the participant shared the importance of having a safe space for needle exchange and for youth. A second participant discussed the possibility of having needle exchange, harm reduction services, which accommodate injection drug users by travelling to various locations within the community,

*In [out of province location] I use to be a part of this group, they would drive around to like the local crack shacks type deal and they would drop off new supplies to them [injection drug users]. There was like a local number you could call and people would drive over stuff for you and take your dirties for you* (Female participant, urban sharing session #1).

Some participants also discussed their experiences learning about the benefits of safe injection sites, such as that offered in East Vancouver, British Columbia. And, interestingly, two participants expressed their past efforts and current interests in establishing such a service in the province of PEI,

*I was actually part of a group there a couple of months ago with a community worker and what we were going to do is we were going to make a building like a safe injection center where people could go in and do what you need to do and get clean needles and leave. We wouldn't supply any drugs whatsoever just the clean things that you need to prevent that [HIV/HCV] from happening. We were actually thinking of doing that but we got shut down for it, which is unfortunate because we kind of really need that* (Female participant, urban sharing session #1).



While participants thoroughly discussed the reduction of harms associated with IDU, few suggestions were put forth regarding the reduction of harms associated with sex and tattooing. One suggestion which was however brought forth was to provide condom distribution machines in school washrooms. Youth participating in the urban sessions shared their experiences petitioning for this with a past community member and community worker, *“We started a petition to get condom machines in schools but we didn’t end up finishing”* (Female participant, urban sharing session #2). Participants stated that condom machines should not only be present in high schools, but in junior highs as well, *“Well even in junior high people go on about how they had sex. I heard so many kids around 13 and 14 say that”* (Female participant, urban sharing session #2). In addition to the reduction of harms associated with IDU and sex, some participants also touched on those harms potentially resulting from tattoos.

Suggestions concerning the reduction of harms relating to tattooing involved the creation and/or implementation of stricter policies within tattoo shops. From community programming, youth participating in the urban sessions learned about proper procedures for tattooing. Community programs also provided youth with knowledge surrounding best steps when finding a tattoo artist and getting a tattoo. As one youth shared, *“And we talked too about like if you go and get tattoos and stuff like that and what to look for. And there’s little cards if you get piercings, too, to know what to ask”* (Female participant, urban sharing session #1). Participants also discussed the importance of autoclaves, which sterilize tattoo and piercing equipment,

*Yeah me and [community member/worker] did that, we went to every tattoo house in Charlottetown and only two of them had them [an autoclave]. They didn’t*

*really answer at first and then [community member] explained why we were there. And when they said they didn't have one she said 'you're lucky you don't get shut down' and that's all she said and we just walked out* (Female participant, urban sharing session #1).

From these experiences, participants expressed feeling better prepared when seeking tattoos or piercings; however, participants also expressing the need for more rigorous precautions to be taken by those seeking tattoos and by those providing tattoo services.

**Culture.** Reading and Wien (2009) describe culture as an intermediate determinant of Aboriginal peoples' health. In addition to systems and the reduction of harms, culture emerged in this research as a core theme and an intermediate determinant which influences prevention and risk to HIV and HCV. Aboriginal culture as a determinant of health encompasses traditional and spiritual elements. These include spiritual beliefs, traditional ceremonies, language, traditional medicines, dance, drumming, songs, and stories (Mi'kmaq Association for Cultural Studies, 2013). The Aboriginal youth who participated in this study shared how many of these elements build HIV and HCV prevention in their own lives and communities. Figure 10 presents participants' photographs illustrating culture.



*Figure 10.* Participants' photographs illustrating culture

Culture provided youth with healing, motivation, and support during experiences of troubles and sickness. For example, culture was described as a means for healing for community members who may be living with HIV or HCV, and for youth who were seeking motivation to stop using substances. As one participant shared, *“It makes you think of your culture and makes you want to stop [substance use]. It makes you want to live for something and do something with your life”* (Female participant, urban sharing session #2). Similarly, a second participant shared,

*You have culture to go back to if you're, you know, if you're sick. If you're sick, I just have to find the words, if you're a drug user or an alcoholic you know people always go back to your culture and they go from there so I think that culture is an important topic* (Male participant, rural sharing session #2).

Thus, youth viewed elements of culture to provide healing and to be a foundation for health and well-being. Such elements included the use of traditional medicines and the connection to community togetherness, reflecting the value of each community member being connected to one another.

In addition to the provision of healing through cultural support and spiritual belief, rural participants discussed the power of the natural environment in providing support and healing in times of need (see figure 11 and figure 12). In particular, the natural environment provided a source of comfort, peace, and once again motivation for the prevention of substance use. As one participant shared,

*Yeah, I took a picture of the harbor out front because it doesn't really like represent HIV or anything but like it's a good place to heal and feel good about yourself, is out there. And if you did that, if you go to that area you kind of feel like at peace with yourself than you don't have to like shoot needles, you know what I mean? (Female participant, rural sharing session #2).*

This quote reflects the holistic cultural values shared by some participants. For instance, Mi'kmaq teachings speak of all things – plants, animals, people – being connected to one another. Thus, the connection between the natural environment and peoples' health is reflected through this avenue of healing (Mi'kmaq Association for Cultural Studies, 2013). This particular means of healing also reflects the cultural teachings of health being holistic, involving physical, emotional, spiritual, and mental components. For instance, the previous quote illustrates mental, emotional, and spiritual health influencing behaviors such as IDU, in turn affecting physical well-being. Discussion surrounding the natural environment was primarily present within rural sharing sessions.



*Figure 11.* Youth's photographs of the natural environment as a source of healing (a)



*Figure 12.* Youth's photographs of the natural environment as a source of healing (b)

Additionally, culture provides an avenue for access to HIV and/or HCV related information and resources (i.e., condoms) through cultural events and groups (see Figure 13). That is, youth participants discussed attending such events and groups to celebrate, connect with, and identify with culture, and while at these event/groups youth would access prevention information and resources. Male participants in both rural and urban sharing sessions discussed experiences in drum groups, where male participants were provided with HIV/HCV related information, in addition to condoms. These were provided to participants through community contacts who would bring pamphlets, condoms, and other resources on drumming trips. Additionally, drum groups provided a

space where male youth could focus on the drum rather than on other activities. As one youth shared,

*Well [community member/worker] always tells us, he's like 'you're drumming, that keeps you away from girls and stuff'. Because girls ain't allowed around the drum. So when we're drumming there's barely any girls around. But even after we're done he tells us, 'just don't do nothing, if you want to do something just grab a condom'. And he works at the health center and he even has a bunch of pamphlets in the truck and we hand them out when we go on trips in the US and Nova Scotia (Male participant, urban sharing session #1).*

While male participants did not speak of why such information and resources were specifically provided in drum groups, this may be related to the purpose of the drum. Traditional to the Mi'kmaq culture, this purpose is to provide teachings and life through the beat of the drum, promoting oneness between people and nature. Drum groups also provide male youth with the opportunity to learn traditions and songs, which tell of Mi'kmaq history (Mi'kmaq Association for Cultural Studies, 2013). The prevention teachings offered in drum groups may therefore be related to the traditional purposes of such groups, encompassing the importance of learning and experiencing. Interestingly, female youth did not discuss a gender-specific safe space for experiencing cultural celebration and receiving prevention information. Thus, gender-specific safe, cultural spaces may be an important topic of future investigation in order to discover novel prevention efforts for young male and female Aboriginal youth of PEI.



In addition to cultural groups, cultural events such as Pow-Wow trails provided both male and female participants with an opportunity to discuss HIV and HCV related information, share this information, and distribute resources. As one participant said, *“On Pow-Wow trails we would have our little [community program] thing set up and we’d give out condoms and information”* (Female participant, urban sharing session #1). Often, youth would also purchase condoms when traveling on Pow-Wow trails, *“I remember us going to Pow-Wow trails and we’d stop at the gas station before we got to the bridge and every one of us would go in and buy a box of condoms”* (Female participant, urban sharing session #1). A second participant shared, *“And my drum keeper is like, ‘Don’t be embarrassed, I’m keeping myself safe, I don’t want you guys coming up here and getting something’. So we got like a big bag [of condoms] sitting in our truck every Pow-wow trail”* (Male participant, urban sharing session#1). Thus, events and groups which celebrate cultural traditions were also an avenue through which both rural and urban youth accessed HIV/HCV related prevention information and resources.

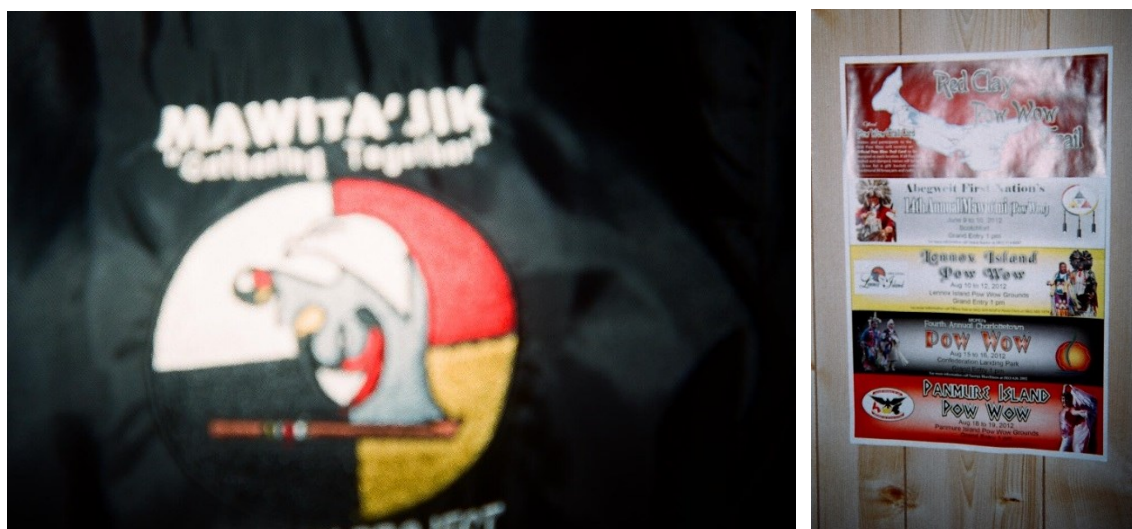


Figure 13. Youth’s photographs representing cultural groups and cultural events

### **Distal Determinants of HIV and HCV Prevention and Risk**

According to Reading and Wien (2009), distal determinants of Aboriginal peoples' health include colonialism, racism and social exclusion, and self-determination. Similarly, youth's stories surrounding racial discrimination and social exclusion within the school system are telling of the distal factors which influence the wellbeing of Aboriginal youth of PEI. A subtle trend of stigma was also expressed by youth, being stigma surrounding the illness of HIV and AIDS. Therefore, racial discrimination, social exclusion, and stigma are distal factors influencing the prevention of HIV/HCV among Aboriginal youth of PEI.

A key distal determinant of Aboriginal peoples' health identified by past researchers, colonization, was not explicitly discussed by the youth participating in this research. While experiences of racial discrimination and social isolation were indeed shared, youth did not speak of intergenerational trauma, residential schools, or other colonial activities. This may signify youth's enthusiasm toward focusing on the present and, more notably, on the future. For instance, youth expressed various ideas toward health promotion and HIV/HCV prevention initiatives for the future and especially for future generations. This focus on the present and future, and this provision of future prevention ideas, may also represent youth's enthusiasm toward Aboriginal youth's self-determination.

### **Moving Forward**

As noted, youth expressed many ideas regarding future health promotion and HIV/HCV prevention initiatives for Aboriginal youth of PEI. Several of such ideas have already been reviewed, for example the establishment of a safe injection site and a



community-based needle exchange site. In discussing additional directions for the future, youth emphasized the importance of HIV and HCV prevention. Youth discussed the importance of prevention not only for the current generation, but also for generations of the future, *“I think this is a very important topic that needs to be discussed and to prevent our kids from it too, right. (...). This is something that needs to be addressed in our community”* (Male participant, rural sharing session #1).

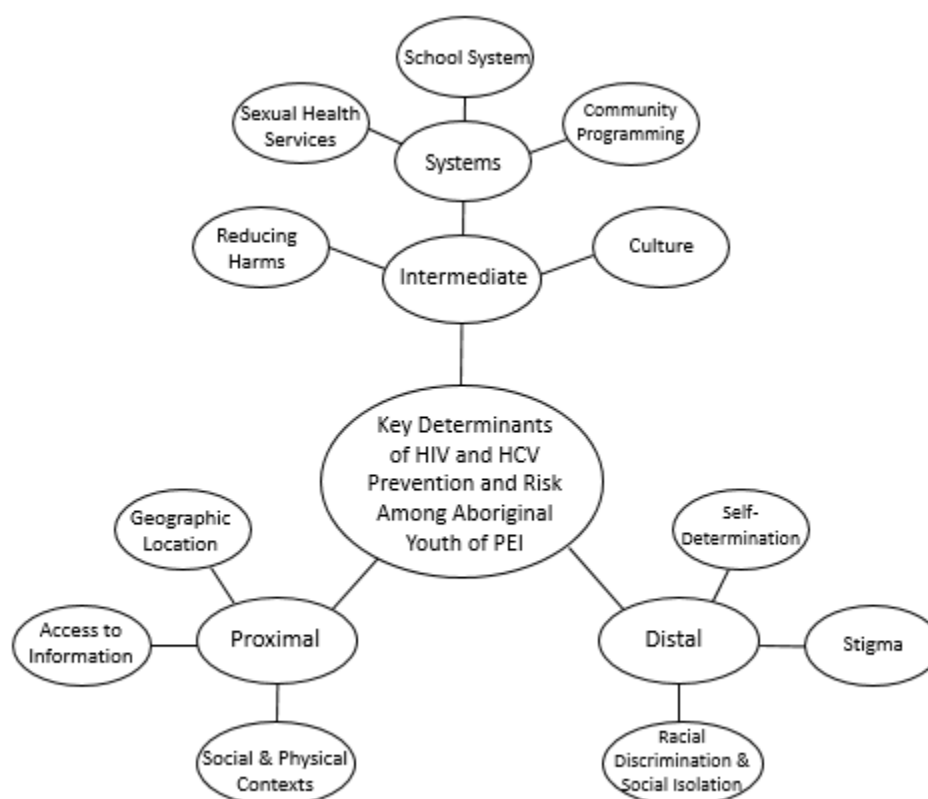
Firstly, youth discussed improving access to HIV and HCV related information, a proximal determinant of HIV/HCV prevention. Youth discussed the importance of sharing information with peers, family, and community members, and youth also discussed best practices for how information might be shared. As one participant suggested, *“We just need to share our knowledge, let people know what we know. Word of mouth goes pretty far”* (Female participant, urban sharing session #3). Participants expressed the need for youth educators within the community, and also discussed the need for information sharing approaches that would overcome stigma often attached to the topics of HCV, HIV, and AIDS. More generally, youth’s overarching message surrounding the sharing of HIV/HCV related information was to *“Go bigger with it”* (Female participant, urban sharing session #1).

Second, participants discussed the need to increase access and uptake of HIV/HCV related health services, an intermediate determinant of HIV/HCV prevention. Youth suggested that STI testing and needle exchange services be better advertised. Further, youth suggested that proper protocols for the disposal of needles be better established within the community, perhaps by use of posters or additional needle disposal bins within community locations (i.e., bars, dining locations, schools, parks). An

additional suggestion put forth by youth included the provision of condom machines within school settings.

### **A Model for the Key Determinants of HIV and HCV Prevention and Risk Among Aboriginal Youth of PEI.**

In its entirety, this chapter puts forth a model for the key determinants of HIV and HCV prevention and risk among Aboriginal youth of PEI. Provided in figure 14, this model was developed according to the framework for thematic network analysis, as described by Attride-Sterling (2001). Figure 14 illustrates the determinants previously described in a format which recognizes the global theme of this study (key determinants of HIV and HCV prevention and risk). Radiating from the global theme, this network also presents organizing themes (proximal, intermediate, and distal determinants), and finally the basic themes which were the core emergent themes and subthemes identified from the data. Given that geographic location, racial discrimination and social isolation, stigma, and self-determination emerged as trends throughout various core themes and subthemes, these trends are included in this model. When examining this thematic network, it is important to recognize the intersecting nature of all basic themes.



*Figure 14.* A thematic network for the key determinants of HIV and HCV prevention and risk among Aboriginal youth of PEI (a)

### **Chapter Summary.**

In accordance with the core themes and subthemes identified from this analysis, the key determinants of HIV and HCV prevention and risk among Aboriginal youth of PEI encompass proximal, intermediate, and distal factors, which interact and build upon one another. These determinants also transform across the life course and vary based on rural/urban location. Key proximal determinants identified from this analysis include social and physical contexts in addition to access to information. Key intermediate determinants include systems (health, school, and community programming), the reduction of harms, and culture. Geographic location, racial discrimination and social

isolation, stigma, and self-determination also arose as trends throughout core themes and subthemes, and were thus categorized as proximal and distal determinants of health.

This chapter reviewed the determinants of health listed above, and also presented directions for future health promotion and HIV/HCV prevention initiatives. Finally, this chapter put forth a thematic network, or model, for the key determinants of HIV and HCV prevention and risk among Aboriginal youth of PEI. Chapter five will explore the emergent core themes and subthemes of this analysis in greater detail, with particular attention being paid to culturally competent and age-appropriate health promotion initiatives for Aboriginal youth in PEI.

## Chapter 5: Discussion

This research sought to address the following research questions: (1) What are the key social determinants of HIV and HCV prevention specific to Aboriginal youth living in rural and urban Prince Edward Island? What are the key determinants of HIV and HCV risk?; and (2) In what ways can this knowledge be integrated into HIV and HCV prevention? To address these questions, a thematic network analysis of the data was conducted, according to the methods of analysis set forth by Attride-Stirling (2001).

Emergent core themes and subthemes showed congruency with Reading and Wien's *Integrated Life Course and Social Determinants Model of Aboriginal Health*; as such, emergent core themes and subthemes were presented in terms of proximal, intermediate, and distal determinants of HIV and HCV prevention and risk among Aboriginal youth of PEI. Proximal determinants identified from this analysis included social and physical contexts, in addition to access to information and geographic location. Intermediate determinants included systems (health, school, and community programming), the reduction of harms, and culture, while distal determinants included self-determination, stigma, racial discrimination, and social isolation. Provided by the voices of Aboriginal youth of PEI, directions toward future health promotion and HIV/HCV prevention initiatives were also identified. Finally, a key thematic network was developed, illustrating emergent themes, subthemes, and trends by means of a visual model (see Figure 14).

This chapter will further explore the emergent themes listed above, again in the context of proximal, intermediate, and distal determinants of health, and with regard to urban versus rural location. This chapter will also provide a reflection on the context-

specific and fluid nature of prevention and risk, in addition to the opportunities and challenges posed in using a model for the social determinants of health. Finally, this chapter will detail applications of the findings toward culture- and youth- friendly health promotion initiatives, including recommendations toward HIV/HCV prevention policies and programs for Aboriginal youth of PEI.

### **Determinants of HIV and HCV Prevention and Risk**

Proximal determinants of health are characteristics within one's immediate surroundings that directly impact physical, emotional, spiritual, and/or mental health. Identified by previous literature, proximal determinants of Aboriginal peoples' health include employment, income, food security, and the physical environment (Reading & Wien, 2009). More specifically, past literature has identified proximal determinants of HIV and HCV risk among Aboriginal youth living in Toronto, including the presence of HIV/AIDS in the participants' communities, poverty, abuse, and colonization (Larkin et al., 2007).

The proximal determinants of HIV/HCV prevention and risk identified in the current study show similarities to those previously identified. That is, physical aspects of the environment (i.e., needles, neighbourhood disadvantage) and the presence of HIV/AIDS in participants' communities were identified as determinants of HIV/HCV prevention and risk. However, some determinants identified within the literature did not emerge during this analysis, while several determinants which did emerge were not explicitly recognized in past research. For example, specific injecting environments and peer pressure, identified as factors of influence toward IDU by Rhodes et al. (2005), did not emerge as key determinants in this study. This may be influenced by the demographic

of the participant population, being that no participants shared experiences actually partaking in IDU. On the other hand, participants spoke of access to information, the natural environment, and community support, which were factors unidentified in the existing literature surrounding specific determinants of HIV/HCV risk and/or prevention. Of note, some factors (i.e., community support, the natural environment) were directly related to prevention, while others (i.e., neighbourhood disadvantage, the presence of needles) were directly related to risk.

The intermediate determinants of HIV/HCV prevention and risk identified from this analysis also show similarities to those identified by past researchers. According to Reading and Wien (2009), intermediate determinants of Aboriginal peoples' health encompass community infrastructure, resources, and systems, which are often the origin of proximal determinants. Past research has examined the educational system and sexual health services (i.e. STI testing) as they relate to HIV/HCV prevention (Kirby, Laris, & Rolleri, 2007; Mill et al., 2008); and, both school systems and sexual health services emerged as subcomponents of a core theme, systems, in this analysis. Additionally, culture has been described as a fundamental determinant of health among Aboriginal peoples, and emerged in this study as a core theme and an intermediate determinant of HIV/HCV prevention among Aboriginal youth of PEI (Reading & Wien, 2009). Culture provided youth with healing, motivation, information, and resources, reflecting values held within Aboriginal communities including holistic perspectives, the connection between all things, and the value of teaching and learning. Youth would attend cultural ceremonies to celebrate, connect with, and identify with culture, and at these ceremonies youth would also receive HIV/HCV prevention information and resources.

As identified in previous research, distal determinants of Aboriginal peoples' health include racism and social exclusions, self-determination, and colonization (Smylie, 2004). Although colonization has been a significant piece of this discussion in past research, youth did not explicitly speak of colonization, including residential schooling or intergenerational trauma, during the sharing sessions. Rather, youth spoke of prevention ideas for the present and the future to help promote the health of generations to come. This emphasis on moving forward reflects youth's value in moving on from past and current inequities in order to create a healthy space for Aboriginal youth in future generations.

While racial discrimination, social exclusion, and stigma did not emerge as core themes from this analysis, these factors arose as trends interwoven throughout youth's various stories. For example, youth felt uneasy when being tested for HIV, due to the general stigma which surrounds HIV and AIDS. Additionally, experiences of social exclusion and racism were discussed by youth exclusively within the context of the school systems, suggesting the importance of inclusive, safe-spaced, and culturally competent approaches to education, and specifically health promotion education given the context of this research. Additionally, the experiences of racism and social exclusion were almost entirely shared by youth living in urban centres; as such, it is essential that context and place be considered within the discussion of health promotion and HIV/HCV risk and prevention.

### **The Influence of Urban and Rural Location**

The findings of this study build upon the current literature by considering the importance of place within HIV/HCV prevention and risk. That is, the findings of this



study speak to the differences in the experiences of youth living in diverse locations, and to the determinants of prevention and risk among Aboriginal youth in both urban *and* rural PEI.

The analysis of this study identified several differences in the HIV/HCV prevention and risk experiences of Aboriginal youth living in rural PEI, as compared to Aboriginal youth living in urban PEI. For instance, neighbourhood disadvantage appeared more visible to youth of urban locations, being that youth would see more needles within the physical environment of neighbourhoods having negative reputations or lower income residents. Further, youth living in urban PEI were more likely to access HIV/HCV related information from community programs or contacts, reflecting an increased availability of programming in urban locations. In contrast, Aboriginal youth living in rural areas of PEI were likely to access HIV/HCV related information through real life experiences, or through material presented within the school system. Youth living in rural areas of PEI were also more likely to access healing from both the natural environment and cultural experiences, where youth of urban areas discussed only cultural experiences as a means for healing.

Evidently, Aboriginal youth of urban and rural PEI encounter different experiences surrounding the physical environment, the natural environment, and HIV/HCV related information and programs. To a great extent, these different experiences speak to the availability and accessibility of resources required to meet the needs of Aboriginal youth in PEI. For example, youth living in urban areas had not experienced healing by means of the natural environment, whereas youth living in rural areas spoke of this as a means for healing in addition to preventing substance use.

Conversely, youth of rural PEI spoke little of experiences in HIV/HCV related community or cultural programming. These findings suggest the importance of sharing the strengths of rural locations with youth living in urban settings, and conversely sharing the strengths of urban areas with youth living in rural locations.

Indeed, place is very important to the discussion surrounding health promotion and HIV/HCV prevention. That is, opportunities and challenges toward HIV and HCV prevention can be identified in both urban and rural locations. However, it is often peoples living in rural areas or living on reserve who experience a limited availability or accessibility of health related services (Marrone, 2007; Sibley & Weiner, 2011). For example, youth who took part in the rural sharing sessions spoke little of available HIV/HCV related information and community/youth programs. As such, ideal health promotion programming would consider accessibility on the levels of geographic location, in addition to age-appropriateness and cultural inclusion.

Tylee and colleagues (2007) suggest six youth-friendly options for providing accessible health care to young people. These avenues include: (1) community-based health facilities; (2) adolescent health facilities; (3) school/college based health services; (4) health services incorporated into existing community facilities; (5) pharmacies; and (6) outreach services and information provision. Given the limited resources available in the province of PEI, it may be most efficient to use existing infrastructures as a means for distributing HIV/HCV prevention information and services. Therefore, school/college based health services, services incorporated into existing community facilities, and community outreach/information provision may be options best suited for health promotion and HIV/HCV prevention among youth of PEI. After discussing the use of

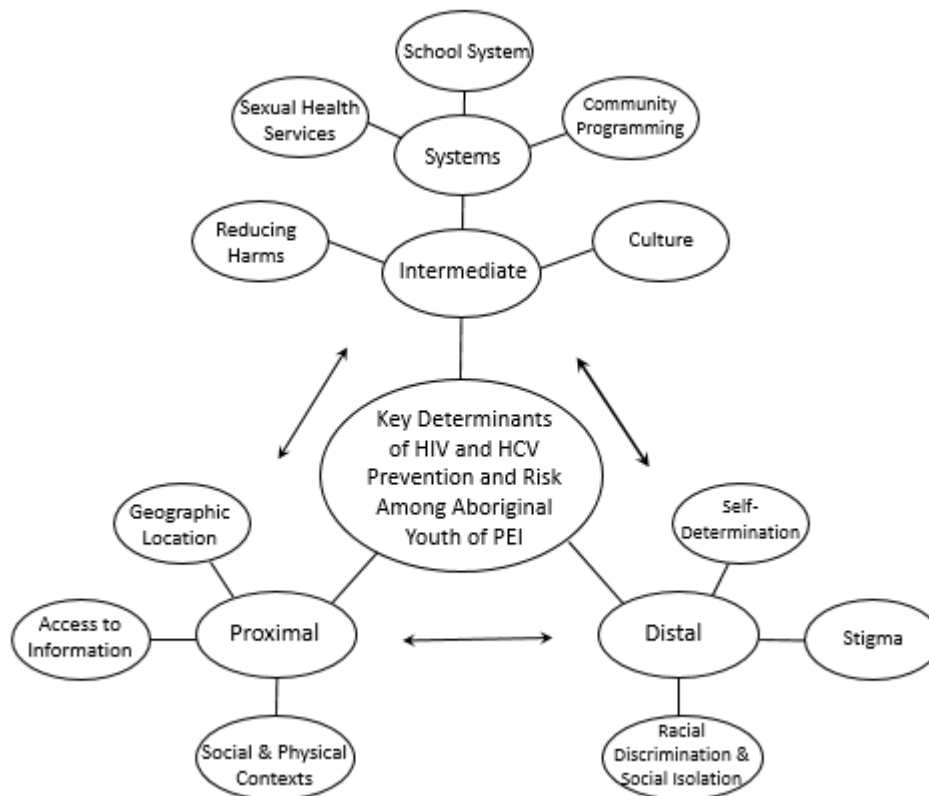
models, methodology, prevention, and risk, this discussion will be revisited by providing key objectives for the practical application of lessons learned from this study.

### **Models and Terminology**

Given that a specific Aboriginal determinants of health model was used to frame this research, emergent core themes and subthemes were broadly categorized into proximal, intermediate, and distal determinants of health. It must be noted, however, that such categories are fluid and interrelated, as each determinant interacts with another. In part, this has been described by Reading and Wien (2009), who noted distal determinants to influence the nature of intermediate determinants, and intermediate determinants to influence the nature of proximal determinants. The findings of this study however illustrate that the social determinants of health interact in a complex, non-linear fashion. For example, the proximal determinant of geographic location influenced the availability of community programming and cultural events. Proximal determinants also interacted with one another, as geographic location was described to affect the presence and diversity of needles within the physical environment. Further, the determinant of culture intersected with gender, a key determinant identified in previous literature, as drum groups provided male youth with a safe space of teaching and learning.

Indeed, culture as a key determinant of HIV/HCV prevention provides an ideal representation of the interconnectedness of the determinants of health among Aboriginal peoples. In this research, youth described spiritual and traditional elements of culture to influence community togetherness, access to information, sexual health services, and community programming. To illustrate these complex, circular interactions among the determinants of HIV/HCV prevention and risk among Aboriginal youth of PEI, a slightly

modified thematic network is provided in figure 15, with bidirectional arrows indicating these intricate interactions.



*Figure 15.* A thematic network for the key determinants of HIV and HCV prevention and risk among Aboriginal youth of PEI (b)

In addition to using a model for the social determinants of health, key terms were also used to help frame this study. Two terms central to this study were those of prevention and risk. Prevention and risk are generally viewed to be opposing concepts which are most often examined independently within health promotion research; for example, prevention to HIV and HCV often infers the study of policy and programming, while risk often infers the study of behavior and its consequences. However, in order to successfully prevent HIV and HCV among Aboriginal youth, it is essential that risk be

addressed not in isolation but through preventative, strength-based, and culturally relevant approaches (Brough, Bond, & Hunt, 2004). According to Brough and colleagues (2004), strength based approaches to health promotion not only address health related risks, but they may also acknowledge existing community resources and serve to provide community and cultural identity. This demonstrates the connections between prevention and risk, wherein encouraging determinants of prevention may in fact reshape determinants of risk. This holistic, strength-based perspective is similar to that provided in the Aboriginal Strategy on HIV/AIDS in Canada, developed by the Canadian Aboriginal AIDS Network (Canadian Aboriginal AIDS Network, 2009).

### **Applications for Health Promotion and HIV/HCV Prevention**

The findings of this study carry practical application toward health promotion and HIV/HCV prevention among Aboriginal youth of PEI. In *Table 1*, several recommendations are put forth, based on the findings of this study. These recommendations involve: the availability and access to HIV/HCV related information; the access and use of HIV/HCV related health services; the promotion of community strengths and community connections within HIV/HCV prevention initiatives; and the inclusiveness of prevention, such that needs of diverse youth be considered. Given the importance of establishing goals when seeking to create equity within health systems and health service provision, these recommendations may be useful when creating goals for future health promotion and HIV/HCV prevention efforts for Aboriginal youth in PEI (Gwatkin, Bhuiya, & Victora, 2004).

Table 1. *Recommendations Toward Health Promotion and HIV/HCV Prevention Among Aboriginal Youth of PEI*

Recommendation	Sample Action Items / Questions to Consider
1. Increase availability and access to HIV/HCV prevention information	<ul style="list-style-type: none"> <li>a. Provide peer education training to encourage conversation between family members and friends</li> <li>b. Employ youth educators within the community</li> <li>c. Ensure that information circulated is culturally relevant and age appropriate</li> </ul>
2. Increase HIV/HCV related health service access and use	<ul style="list-style-type: none"> <li>a. Increase public awareness of available services, such as needle exchange services, STI testing services, and needle disposal locations</li> <li>b. Establish a community-based needle exchange service</li> <li>c. Establish a community-based safe injection site</li> </ul>
3. Promote community strengths and community connections within HIV/HCV prevention initiatives	<ul style="list-style-type: none"> <li>a. Promote existing youth programs, social supports, the natural environment, local health centres, community successes, and community values as means for prevention</li> <li>b. Encompass culture and tradition into prevention initiatives</li> <li>c. Encourage lasting relationships between youth and community members/workers. For example, provide incentives for the retention of community health workers.</li> </ul>

Table 1. *Recommendations Toward Health Promotion and HIV/HCV Prevention Among Aboriginal Youth of PEI (continued)*

Recommendation	Sample Action Items / Questions to Consider
4. Ensure HIV/HCV prevention initiatives are inclusive, providing a safe space for diverse youth	<p>Questions to consider:</p> <ul style="list-style-type: none"> <li>a. Is your program or service equally accessible to youth of urban and rural PEI?</li> <li>b. Is your program or service accessible to youth involved with the correctional system and/or uninvolved in the public school system?</li> <li>c. Does your program, service, or educational setting overcome racial discrimination, stigma, and social exclusion?</li> <li>d. Does your program, service, or educational setting provide a safe, comfortable, and culturally-appropriate space for Aboriginal youth?</li> </ul>

Of note, several action items presented in *Table 1* have already been demonstrated by Aboriginal AIDS Service Organizations serving the Atlantic Provinces. For example, peer-based, culturally-relevant, and youth-focused activities are regularly presented by Healing Our Nations and the Native Council of Prince Edward Island's *Hep'd Up on Life* program (Healing our Nations, 2013; O'Neill, 2008). Still, it is important that such recommendations be accessible to programmers at health centres (i.e., on reserve), youth coordinators, policy makers, and other community workers. It is also important to ensure that information and resources be available to Aboriginal youth of all geographic locations. Indeed, youth of both rural and urban locations were eager to participate in this

research, and eager to learn about HIV/HCV prevention information. Youth were also happy to share their voices for the present and future improvement of HIV/HCV prevention efforts in PEI.

### **Summary**

This youth-oriented, community-based research was conducted to identify key determinants of HIV/HCV prevention and risk among Aboriginal youth of PEI, and to identify applications of this information toward health promotion and HIV/HCV prevention initiatives. Data were collected through interactive, iterative sharing sessions, which incorporated oral story-telling, photo-voice, and lessons in cultural photography. A thematic network analysis of transcripts yielded emergent core themes and subthemes, which were explored within the context of proximal, intermediate, and distal determinants of health. Key proximal determinants identified from the analysis include social and physical contexts, access to information, and geographic location. Intermediate determinants include systems (health, school, and community programming), the reduction of harms, and culture, while distal determinants include racial discrimination and social isolation, stigma, and self-determination.

The findings of this study carry several applications toward future health promotion and HIV/HCV prevention programming in PEI. For instance, four recommendations were put forth, encompassing: the availability and access to HIV/HCV related information; the access and use of HIV/HCV related health services; the promotion of community strengths and community connections within HIV/HCV prevention programming; and the inclusiveness of prevention initiatives. The findings of this study also highlight the interacting, intersecting nature of the social determinants of



health, the fluidity between risk and prevention, and the differing experiences of Aboriginal youth living in rural versus urban PEI. Finally, it is suggested from this study that key determinants of prevention, identified by Aboriginal youth of PEI, be incorporated and encouraged within prevention initiatives in order to reshape identified determinants of risk. That is, strength-based and community-engaged approaches must be considered, not only as a means for prevention, but also as a means for empowering youth, acknowledging community resources, and encouraging community and cultural identity.

## References

- Andersson, N., & Ledogar, R. J. (2008). The CIET Aboriginal youth resilience studies: 14 years of capacity building and methods development in Canada. *Pimatisiwin*, 6, 65-88.
- Atkinson, J., Nelson, J., & Atkinson, C. Trauma, transgenerational transfer and effects on community wellbeing. *Working together: Aboriginal and Torres Strait Islander and mental health and wellbeing principles and practice*. Canberra: Department of Health and Ageing (2009): 135-44.
- Attride-Stirling, J. (2001). Thematic networks: An analytic tool for qualitative research. *Qualitative Research*, 1, 385-405.
- Blackstock, C., & Trocmé, N. (2005). Community based child welfare for Aboriginal children: Supporting resilience through structural change. *Social Policy Journal of New Zealand*, 25, 12-33.
- Bombay, A., Matheson, K., & Anisman, H. (2009). Intergenerational trauma: Convergence of multiple processes among First Nations peoples in Canada. *International Journal of Indigenous Health*, 5, 6-47.
- Brough, M. K., Bond, C., & Hunt, J. (2004). Strong in the city: Toward a strength based approach to Indigenous health promotion. *Health Promotion Journal of Australia*, 15, 215-220.
- Browne, A. J., & Varcoe, C. (2006). Critical cultural perspectives and health care involving Aboriginal peoples. *Contemporary Nursing*, 22, 155-167.
- Bustamante, R. M., Nelson, J. A., & Onwuegbuzie, A. J. (2009). Assessing schoolwide

- cultural competence: Implications for school leadership preparation. *Educational Administration Quarterly*, 45, 793-827.
- Canadian Aboriginal AIDS Network. (2009). Aboriginal Strategy on HIV/AIDS in Canada II. Retrieved from <http://www.caan.ca/wp-content/uploads/2012/05/ASHAC.pdf>
- Canadian Aboriginal AIDS Network. (2010). National Aboriginal Youth Strategy on HIV & AIDS in Canada. Retrieved from [http://caan.ca/wpcontent/uploads/2012/05/NAYSHAC\\_CAAN\\_20101.pdf](http://caan.ca/wpcontent/uploads/2012/05/NAYSHAC_CAAN_20101.pdf)
- Canadian Aboriginal AIDS Network. (2012). Assessing community readiness & Implementing risk reduction strategies manual. Retrieved from <http://caan.ca/wp-content/uploads/2012/05/CR-manual-eng.pdf>
- Canadian Institute of Health Research. (2010). *Tri-Council policy statement: Ethical conduct for research involving humans*. Retrieved from [http://www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPS\\_2\\_FINAL\\_Web.pdf](http://www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf)
- Carlson, J. C. (1994). *Journey from Fisher River: A Celebration of the Spirituality of a People Through the Life of Stanley McKay*. Toronto: United Church Publishing House.
- Castleden, H., Garvin, T., & Huu-ay-aht First Nation. (2008). Modifying photo-voice for community-based participatory Indigenous research. *Social Science & Medicine*, 66, 1393-1405.
- Catalani, C., & Minkler, M. (2010). Photovoie: A review of the literature. *Health Education & Behavior*, 37, 424-451.
- Christian, W. M., & Spittal, P. M. (2008). The cedar project: Acknowledging the pain of

our children. *Lancet*, 372, 1132-1133.

Creswell, J. W. (2007). *Qualitative inquiry and research design. Choosing among five approaches*. Thousand Oaks: Sage.

Czyzewski, K. (2011). Colonialism as a broader social determinant of health. *The International Indigenous Policy Journal*, 2. Retrieved from <http://ir.lib.uwo.ca/iipj/vol2/iss1/5>

Denzin, N. K., & Lincoln, Y. S. (2008). Critical methodologies and Indigenous inquiry. In Denzin, N. K., Lincoln, Y. S., & Smith L. T. (Eds.), *Handbook of Critical Indigenous Methodologies* (1-21). California: SAGE Publications.

Devries, K. M., Free, C. J., Morison, L., & Saewyc, E. (2008). Factors associated with the sexual behaviour of Canadian Aboriginal young people and their implications for health promotion. *American Journal of Public Health*, 99(5), 855-862. doi: 10.2105/AJPH.2007.132597

Donovan, B., & Ross, M. W. (2000). Preventing HIV: Determinants of HIV. *The Lancet*, 355, 1897-1901.

Drew, S. E., Duncan, R. E., & Sawyer, S. M. (2010). Visual storytelling: A beneficial but challenging method for health research with young people. *Qualitative Health Research*, 20, 1677-1688.

Duncan, K. C., Reading, C., Borwein, A. M., Murray, M. C. M., Palmer, A., Michelow, W., . . . Hogg, R. S., (2011). HIV incidence and prevalence among Aboriginal peoples in Canada (2011). *AIDS and Behavior*, 15, 214-227.

Dwyer, S. C., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods*, 8, 53-63.

Eyles, J., Brimacombe, M., Chaulk, P., Stoddart, G., Pranger, T., & Moase, O. (2001).

- What determines health? To where should we shift resources? Attitudes towards the determinants of health among multiple stakeholder groups in Prince Edward Island, Canada. *Social Science & Medicine*, 53, 1611-1619.
- Flicker, S. et al. (2012). Taking Action! Art and Aboriginal Youth Leadership for HIV Prevention. Toronto, On.
- Fournier, S., & Crey, E. (1997). *Stolen from our embrace: The abduction of First Nation's children and the restoration of Aboriginal communities*. Vancouver: Douglas and McIntyre. P. 111-224.
- Graham, H. (2004). Social determinants and their unequal distribution: Clarifying policy understandings. *The Milbank Quarterly*, 82, 101-124.
- Graneheim, U. H., & Lundman, B. (2003). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24, 105-112.
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In *Handbook of Qualitative Research*. Thousand Oaks, CA
- Gwatkin, D. R., Bhuiya, A., & Victora, C. G. (2004). Making health systems more equitable. *Lancet*, 364, 1273-1280.
- Halfon, N., & Hochstein, M. (2002). Life course health development: An integrated framework for developing health, policy, and research. *The Milbank Quarterly*, 80, 433-479.
- Healing our Nations. (2012). No Harm in Trying Atlantic Harm Reduction Gathering. Retrieved from <http://www.allnationshope.ca/Documents/Final%20Harm%20Reduction%20Gathering%20Agenda.pdf>
- Healing our Nations. (2013). Our Services. Retrieved from <http://www.hon93.ca/inside>

.php?mn=6

- Health Canada (2004). HIV/AIDS among Aboriginal people in Canada: A continuing concern. *HIV/AIDS Epi Update*.
- Health Canada. (2006). *Enhanced Surveillance of Risk Behaviours Among Injection Drug Users in Canada*. Retrieved from [http://www.phac-aspc.gc.ca/i-track/sr-re-1/pdf/itrack06\\_e.pdf](http://www.phac-aspc.gc.ca/i-track/sr-re-1/pdf/itrack06_e.pdf)
- Hodge, F. S., Pasqua, A., Marquez, C. A., Geishirt-cantrell, B. (2002). Utilizing traditional story telling to promote wellness in American Indian communities. *Journal of transcultural Nursing, 13*, 6-11.
- Human Resources Development Canada. (1999). *Statistical Overview of Prince Edward Island*. Retrieved from [www.pe.hrdc-drhc.gc.ca/ca/common/stat-oview.html](http://www.pe.hrdc-drhc.gc.ca/ca/common/stat-oview.html)
- Hunter, L. M., Logan, J., Goulet, J., & Barton, S. (2006). Aboriginal health: Regaining balance and culture. *Journal of Transcultural Nursing, 17*, 13-22.
- Joe, R. (1996). *Song of Rita Joe Autobiography of a Mi'kmaq Poet*. Charlottetown: Ragweed Press.
- Kirby, D. B., Laris, B. A., & Roller, L. A. (2007). Sex and HIV education programs: Their impact on sexual behaviors of young people throughout the world. *Journal of Adolescent Health, 40*, 206-217.
- Kirby, D. B., Laris, B. A., & Roller, L. A. (2009). Impact of sex and HIV education programs on sexual behaviors of youth in developing and developed countries. Retrieved from: <http://dspace.cigilibrary.org/jspui/bitstream/123456789/8726/1/Impact%20of%20Sex%20and%20HIV%20Education%20Programs%20on%20>

Sexual%20Behaviours%20of%20Youth%20in%20Developing%20and%20Devel  
oped%20Countries%202005.pdf?1

- Kirmayer, L., Sehdev, M., Whitley, R., Dandeneau, S., & Isaac, C. (2011). Community resilience: Models, metaphors and measures. *International Journal of Indigenous Health Promotion, 5*, 62-117.
- Kirmayer, L., Simpson, C., & Cargo, M. (2003). Healing traditions: Culture, community and mental health promotion with Canadian Aboriginal peoples. *Australasian Psychiatry, 11*, S15-S23.
- Larkin, J., Flicker, S., Koleszar-Green, R., Mintz, S., Dagnino, M., & Mitchell, C. (2007). HIV risk, systemic inequities, and Aboriginal youth. *Canadian Journal of Public Health, 98*, 179-182.
- Lavallee, L. F., & Poole, J. M. (2010). Beyond recovery: Colonization, health and healing for Indigenous People in Canada. *International Journal of Mental Health and Addiction, 8*, 271-281.
- Levine, D., McCright, J., Dobkin, K., Woodruff, A. J., & Klausner, J. D. (2007). SEXINFO: A sexual health text messaging service for San Francisco Youth. *American Journal of Public Health, 98*, 393-395.
- Lustig, M. W., & Koester, J. (2002). *Intercultural competence: Interpersonal communication across cultures* (4th ed.). Boston: Longman.
- Mainline Needle Exchange. (2000). *Aboriginal injection drug users and needle exchange programs: Identifying barriers in Nova Scotia*.
- Majumdar, B. B., Chambers, T. L., & Roberts, J. (2004). Community-based, culturally

- sensitive HIV/AIDS education for Aboriginal adolescents: Implications for nursing practice. *Journal of Transcultural Nursing*, 15, 69-73.
- Marmot, M. (2000). Social determinants of health: From observation to policy. *The Medical Journal of Australia*, 172, 379-382.
- Marmot, M., Friel, S., Bell, R., Houweling, T. A., & Taylor, S. (2008). Closing the gap in a generation: Health equity through action on the social determinants of health. *The Lancet*, 372, 1661-1669.
- Maronne, S. (2007). Understanding barriers to health care: A review of disparities in health care services among Indigenous populations. *International Journal of Circumpolar Health*, 66, 188-198.
- Mehrabadi, A., Paterson, K., Pearce, M., Sheetal, P., Craib, K. J. P., Moniruzzaman, A., Schechter, M. T., & Spittal, P. M. (2008). Gender differences in HIV and Hepatitis C related vulnerabilities among Aboriginal young people who use street drugs in two Canadian cities. *Women & Health*, 48, 235-236.
- Mi'kmaq Association for Cultural Studies. (2013). *Spirituality*. Retrieved from [http://mikmaqculture.com/index.php/mikmaq\\_history\\_culture/songs](http://mikmaqculture.com/index.php/mikmaq_history_culture/songs)
- Mill, J. E., Jackson, R. C., Worthington, C. A., Archibald, C. P., Wong, T., Myers, T., Prentice, T., & Sommerfeldt, S. (2008). HIV testing and care in Canadian Aboriginal youth: A community-based mixed methods study. *BioMed Central Infectious Diseases*, 8, doi:10.1186/1471-2334-8-132
- Minkler, M. (2005). Community-based research partnerships: Challenges and opportunities. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*, 82, ii3-ii12.
- Minkler, M., & Wallerstein, N. (Eds.). (2003). *Community-based participatory research*



*In health*. San Francisco: Jossey-Bass.

- Mundel, E., & Chapman, G. (2010). A decolonizing approach to health promotion in Canada: The case of the Urban Aboriginal Community Kitchen Garden Party. *Health Promotion International, 25*, 166-173.
- O'Neill, P. (2008). *Posterboard Presentation: Hep'd Up on Life*. Retrieved from [http://www.upei.ca/si/files/si/2008\\_Poster4\\_PamONeill\\_EN.pdf](http://www.upei.ca/si/files/si/2008_Poster4_PamONeill_EN.pdf)
- Patterson, M., Jackson, R., & Edwards, N. (2006). Ethics in Aboriginal research: Comments on paradigms, process and two worlds. *Canadian Journal of Aboriginal Community-Based HIV/AIDS Research, 1*, 47-61.
- Patton, M. Q. (1999). Enhancing the quality and credibility of qualitative analysis. *Health Services Research, 34*, 1189-1208.
- Pearce, M. E., Christian, W. M., Paterson, K., Norris, K., Moniruzzaman, A., Craib, K. J. P., Schechter, M. T., & Spittal, P. M. (2008). The cedar project: Historical trauma, sexual abuse and HIV risk among young Aboriginal people who use injection and non-injection drugs in two Canadian cities. *Social Science & Medicine, 66*, 2185-2194.
- Prince Edward Island Statistics Bureau. (2011). *Prince Edward Island Population Report 2011*. Retrieved from [http://www.gov.pe.ca/photos/original/pt\\_pop\\_rep.pdf](http://www.gov.pe.ca/photos/original/pt_pop_rep.pdf)
- Public Health Agency of Canada (2009). *Epidemiology of Acute Hepatitis C Infection in Canada Results from the Enhanced Hepatitis Strain Surveillance System (EHSSS)*. Retrieved from <http://www.phac-aspc.gc.ca/sti-its-surv-epi/pdf/hcv-epi-eng.pdf>
- Public Health Agency of Canada. (2010). HIV/AIDS among Aboriginal people in

Canada. *HIV/AIDS Epi Update*.

Public Health Agency of Canada. (2011b). *Reported cases and rates of Hepatitis C by province/territory and sex, 2005-2010*.

Public Health Agency of Canada. (2011b). *Summary: Estimates of HIV prevalence and Incidence in Canada, 2011*.

Reading, C. L., & Wien, F. (2009). Health inequalities and social determinants of Aboriginal peoples' health. *National Collaborating Centre for Aboriginal Health*.

Rhodes, T., Singer, M., Bourgois, P., Friedman, S. R., & Strathdee, S. A. (2005). The social structural production of HIV risk among injection drug users. *Social Science & Medicine*, *61*, 1026-1044.

Schnarch, B. (2004). Ownership, control, access, and possession (OCAP) or self Determination applied to research: A critical analysis of contemporary First Nations research and some options for First Nations communities. *Journal of Aboriginal Health*, *1*, 80-95.

Sibley, L. M., & Weiner, J. P. (2011). An evaluation of access to health care services along the rural-urban continuum in Canada. *BMC Health Services Research*, *11*. doi:10.1186/1472-6963-11-20

Smylie, J. (2000). A guide for health professionals working with Aboriginal peoples: The sociocultural context of Aboriginal peoples in Canada. *Journal of Society of Obstetricians and Gynecologists of Canada*, *22*, 1070-1081.

Smylie, J. (2004). The health of Aboriginal peoples. In Raphael, D (Ed.), *Social Determinants of Health Second Edition* (280-301). Toronto: Canadian Scholars' Press Inc.

- Smylie, J., & Anderson, M. (2006). Understanding the health of Indigenous peoples in Canada: Key methodological and conceptual challenges. *Canadian Medical Association Journal*, *175*(6). doi: 10.1503/cmaj.060940
- Spittal, P. M., Craib, K. J. P., Teegee, M., Baylis, C., Christian, W. M., Moniruzzaman, A., & Schechter, M. T. (2007). The cedar project: Prevalence and correlates of HIV infection among young Aboriginal people who use drugs in two Canadian cities. *International Journal of Circumpolar Health*, *66*, 226-240.
- Statistics Canada. (2001). *Geographic Units*. Retrieved from [www12.statcan.ca/English/census01/products/reference/dict/geo049.htm](http://www12.statcan.ca/English/census01/products/reference/dict/geo049.htm)
- Statistics Canada. (2006). *2006 Aboriginal population profile*. Retrieved from <http://www12.statcan.ca/census-recensement/2006/dp-pd/prof/92-594/details/page.cfm?Lang=E&Geo1=CD&Code1=1101&Geo2=PR&Code2=11&Data=Count&SearchText=Kings&SearchType=Begins&SearchPR=01&B1=All&GeoLevel=PR&GeoCode=1101>
- Steenbeek, A., Bailey, G., & Simandl, D (2013). Culturally relevant HIV/AIDS education, prevention, screening and treatment for Canadian Inuit. *Canadian Journal of Public Health*, *104*, e184.
- Strachan, D. P. (2000). The role of environmental factors in asthma. *British Medical Bulletin*, *56*, 865–82.
- Strathdee, S. A., Patrick, D. M., Archibald, C. P., Ofner, M., Cornelisse, P. G. A., Rekart, M., Schechter, M. T., & OèShaughnessy, M. V. (1997). Social determinants predict needle-sharing behaviour among injection drug users in Vancouver, Canada. *Addiction*, *92*, 1339-1347.
- Strathdee, S. A., Hogg, R. S., Martindal, S. L., Cornelisse, P. G. A., Craib, K. J. P.,

- Montaner, J. S. G., O'Shaughnessy, M. V., & Schechter, M. T. (1998). Determinants of sexual risk taking among young HIV-negative gay and bisexual men. *Journal of Acquired Immune Deficiency Syndromes & Human Retrovirology*, *19*, 61-66.
- Strathdee, S. A., Hallett, T. B., Bobrava, N., Rhodes, T., Booth, R., Abdool, R., & Hankins, C. A. (2010). HIV and risk environment for injecting drug users: The past, present, and future. *Lancet*, *376*, 268-284.
- Stratton, T., Jackson, R., & Barlow, K. (2006). Making it our way: A community mobilization tool kit. Canadian Aboriginal AIDS Network: Ottawa.
- Taking Action. (2012). *Taking Action! Art and Aboriginal Youth Leadership for HIV Prevention*. Retrived from <http://www.takingaction4youth.org/>
- Tiesmaki, M. (2011). Harm reduction in Atlantic Canada: Scan of provincial policies. Retrieved From <http://harmreductionatlantic.ca/wpcontent/uploads/2012/04/HaRMs-Policy Scan.pdf>
- Tolman, D. L., & McClelland, S. I. (2011). Normative sexual development in adolescence: A decade in review, 2000-2009. *Journal of Research on Adolescence*, *21*, 242-255.
- Tylee, A., Haller, D. M., Graham, T., Churchill, R., & Sanci, L. A. (2007). Youth-friendly primary-care services: how are we doing and what more needs to be done? *The Lancet*. doi:10.1016/S0140-6736(07)60371-7
- Wang, C. C., & Burris, M. (1997). Photo-voice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior*, *24*, 369-387.
- Wardman, D., Quantz, D., & Clement, K. (2006). HIV/AIDS: Testing and risk behaviors among British Columbia's rural Aboriginal population. *International Journal of*

*Circumpolar Health*, 65, 313-321.

Whitney, D., Trostenlloom, A., & Cooperrider, D. (2010). What is appreciative inquiry?

In *The Power of Appreciative Inquiry*. California: Berrett-Koehler Publishers, Inc.

World Health Organization. (2007). Commission on the Social Determinants of Health –

Achieving Health Equity: From root causes to fair outcomes. Interim Statement.

Geneva: World Health Organization.

## **APPENDIX A:**

### **Principles of Research Collaboration Agreement**

**(Template Prepared by the Canadian Aboriginal AIDS Network)**

#### **Parties**

This document constitutes a Principles for Research Collaboration (PRC) between the community advisory committee of PEI and Pamela Hudson, a Master's student of Health Promotion at the University of Dalhousie, N.S.

The research will be carried out under the terms identified below.

Due to the nature of the Master's program in which Pamela Hudson is enrolled, she will act as the primary researcher on this project.

#### **Purpose**

The purpose of this PRC is to establish a set of principles that guide the conduct of the research project, "*Exploring Key Determinants of HIV/HCV Prevention and Risk: Voices of Aboriginal Youth of Prince Edward Island*" In short, this agreement acknowledges the importance of incorporating cultural values and perspectives into the research process.

#### **Ethical Considerations**

Ethical codes of conduct for research in Aboriginal communities have been articulated in the *Tri-Council Policy Statement*. However, each member of this committee collectively shares the responsibility for raising ethical concerns and issues. Ethical dilemmas are resolved on the basis of the committee striving for a significant degree of consensus.

#### **Duration and Amendments**

This PRC will be in effect throughout the entire research process, from the initiation of the research project through data collection and analysis phases into dissemination of findings. This PRC can be amended upon mutual consent by members of the research advisory committee.

**Principles: Ownership, Control, Access and Possession**

This research acknowledges and supports the principles of ownership, control, access and possession as outlined below:

- Members of the research advisory committee/team acknowledge and respect the Aboriginal right to self-determination, including the jurisdiction to decide about research in their communities. In doing so, the research process shall be built upon meaningful engagement and reciprocity between the researcher and Aboriginal communities. Further, the researcher agrees she will strive to respect the privacy, dignity, culture and rights of Aboriginal peoples.
- Due to the nature of the Master's Program, Pamela Hudson will be the principle researcher on this project; however, this research will strive to include meaningful participation from Aboriginal community members. Therefore, the parties agree they will be jointly involved from beginning to end in the research process, from research formulation, through data collection, analysis and into dissemination of research findings related to the above named project.
- The research advisory team may also strive to demonstrate this support by obtaining and attaching letters of support from Aboriginal community leadership at the local level who may assist as either a member of a research advisory committee or in providing assistance related to the recruitment of participants. Primarily, the task of negotiating letters of support from local Aboriginal communities resides with the principal researcher.
- The research advisory team agrees that they will collectively make decisions on the development of the research process, the process of data collection, the interpretation of results, and dissemination of findings. To fulfill the requirements of the Master's program, Pamela will be fully responsible for writing a final report to be distributed to Dalhousie University. If parties do not wish for the findings to be disseminated, or if a consensus cannot be made with regard to the appropriate interpretation/dissemination route of findings: the findings will not be disseminated beyond the thesis report and presentation required by the Dalhousie Master's program.
- Dissemination activities beyond the thesis report and thesis presentation will be carried out with the equitable involvement of all advisory team members.
- The research questions must not only reflect academic interests but strive to ensure that the research is also relevant and beneficial to Aboriginal communities.

- In dissemination strategies to Aboriginal communities, the research advisory team agrees that the language and manner of sharing research will be appropriate.
- The (purpose of) research project will be explained to all stakeholders (participants and Aboriginal community members) in a language that is appropriate to the Aboriginal community. Likewise, the research team will explain potential risks and benefits in a similar manner.
- The research advisory team agrees they will not sensationalize problems in Aboriginal communities. Rather, they will strive to present a balanced portrait that also focuses equal attention on more positive aspects. As such, the research team understands that they will collaboratively prepare draft findings prior to submission for publication or presentation. The parties agree to review findings in a timely manner (e.g. one month).
- Given that all members of the research advisory team will be provided the opportunity to review and comment on findings prior to publication or presentation, any one member of the team may not, particularly once initial dissemination has occurred, further analyze, publish or present findings resulting from the above mentioned research project unless the entire research team reaches a consensus.
- The primary researcher is responsible for maintaining the integrity of all data collected, such as storing participant consent forms, etc. However, once privacy and confidentiality of participants has been demonstrated, data sets in the form of Atlas.ti computer files may be shared with all members of the research advisory team. In cases of disagreement over transfer of data sets (as described above), the research team will strive to achieve a significant degree of consensus.
- The research advisory team agrees to provide meaningful and appropriate research capacity-building, as indicated by Aboriginal community participants.
- The research advisory team agrees that Aboriginal communities have the right to follow cultural codes of conduct and community protocols. However, rather than end a research relationship, in situations where Aboriginal community members are in disagreement, the research advisory team will strive to resolve conflict towards achieving a significant degree of consensus.
- The research advisory team agrees that it may be necessary for Aboriginal community members (investigators and participants) to seek advice and support from community elders and other community leadership.



## Authorship

Criteria outlined by Huth (1986) will be used as guidelines for authorship of publication based on the findings of the research. The criteria recommend that: (1) all authors must make a substantial contribution to the conception, design, analysis, or interpretation of data; (2) authors must be involved in writing and revising the manuscript for intellectual content; and (3) authors must approve the final draft and be able to defend the published work. Those who have made other contributions to the work (e.g. data collection without interpretation, etc.) or only parts of the above criteria should be credited in the acknowledgements, but not receive authorship. Further,

- The primary researcher, Pamela Hudson, holds responsibility for submitting a final report on the project to Dalhousie University as a requirement for the fulfillment of the Master's of Arts in Health Promotion Program. All team members will be acknowledged in this document given their consent.
- Research project advisors may participate as authors in all other papers, reports, and presentations provided that they fulfill the criteria outlined above.
- All members of the research advisory team will be provided the opportunity to review and comment on findings prior to publication or presentation. Any one member of the research advisory team may further publish or present findings resulting from the above-mentioned research project with the agreement of the primary researcher and the other research advisory team members.
- The explicit permission of an individual or organization must be sought prior to acknowledging their contribution in a paper or presentation.
- A research advisory team member or a partner may choose to include a disclaimer if they do not agree with the content or views presented in a publication. This disclaimer will be included in the final thesis of this project as well as other publications. In the rare situation that the advisory team feels that findings are not suitable for publication or presentation, dissemination of findings will not extend beyond the thesis document and the thesis presentation, which is necessary for the completion of the MA program.

## Bibliography

A number of sources were consulted in preparing these principles of research collaboration. The Canadian Aboriginal AIDS Network acknowledges the contributions of the following sources.

Canadian Aboriginal AIDS Network (2002). *Ownership, Control, Access and Possession Fact Sheet*. Ottawa, Ontario.

Huth, Edward (1985). "Guidelines on Authorship of Medical Papers." American College of Physicians. *Annals of Medicine*, 104: 269-274.

Israel, Barbara, Amy Schutz, Edith Parker and Adam Becker (1998). "Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health." *American Review of Public Health*. Vol. 19: 173-202.

Kaufert, Joseph, Laura Commanda, Brenda Ellias, Roda Grey, Barney Masuzumi, and Kue Young (2000). "Community Participation in Health Research Ethics." *Pushing the Margins: Native and Northern Studies*. Eds. Jill Oaks, Rick Riewe, Maylyn Bennett, Brenda Chisholm. Native Studies Press, University of Manitoba: 50-51.

Kaufert, Joseph, Laura Commanda, Brenda Elias, Roda Grey, T. Kue Young, and Barney Masuzumi (1999). "Evolving Participation of Aboriginal Communities in Health Research Ethics Review: The Impact of the Inuvik Workshop." *International Journal of Circumpolar Health*. Vol. 58 (No. 2): 134-44.

Schnarch, Brian (2002). *Ownership, Control, and Access*. Ottawa, Ontario: National Aboriginal Health Organization. (Unpublished Presentation).



### APPENDIX C: Screening Telephone Script

**[With a potential participant. Researcher will clarify points where uncommon language is used.]**

Hello! Thank you very much for your interest in the research project, *Exploring Determinants of HIV/HCV prevention and risk: Voices of Aboriginal Youth of Prince Edward Island*. My name is Pamela Hudson and I am a Master of Arts student in Health Promotion at Dalhousie University. I am doing this study as part of the research I am completing for my Master's degree.

For this project, I am trying to learn about the factors that influence HIV and Hepatitis C prevention and risk among Aboriginal youth, aged 16-24 years, who live in Prince Edward Island. HIV and Hepatitis C are viruses that can be passed on through unprotected sex with an infected partner and also through injection drug use using dirty needles and/or drug supplies. So, in this project, I am studying topics such as sexuality, injection drug use, health services, and health education programs.

I want to learn more about youth's thoughts on this topic. This research will be carried out in partnership with the Aboriginal community of PEI and will involve discussions with youth. After giving consent, youth who want to participate are invited to attend three sharing sessions. Sessions will be guided by myself and also a member of the Aboriginal community of PEI. Between 6 and 8 youth will be participating in each session and each discussion will take 1.5 to 2 hours. As well, you would be asked to fill out a short survey about yourself and participate in a photo taking activity.

Do you have any questions about this study?

Are you interested in participating?

- **If No:** Okay. Thank you very much for contacting me to learn more about the study. I appreciate your interest. Have a great day!

**If Yes:** Okay, I have a few questions to ask you to make sure you are able to participate.

In order to participate, you must:

- be 16 to 24 years old,
- identify as Aboriginal
- have lived in PEI for at least one year between the ages of 16 and 24

Do you fit these criteria?

- **If No:** Because of the research questions guiding this project, the study is limited to people who fit these criteria. While I really appreciate you contacting me, you are not eligible to participate in the study. Thank you very much for taking the time to find out more about the study.

**If Yes:** HIV and HCV are sensitive topics of discussion; therefore, it may be uncomfortable talking about these issues. The next question I have for you is: are you comfortable speaking to a female, a community member, and peers about your thoughts on HIV and HCV risk and prevention?

- **If No:** As talking to a female and a community member about this topic is a requirement for this study, you are not eligible to participate. Thank you very much for your interest in this study, and I appreciate you taking the time to find out more about the study.

**If Yes:** Okay. Please note, for practical reasons it is necessary that you consent to be audio-recorded throughout the session, which may mean that I will use some of your direct quotes. I will remove all personally-identifying information from the quotes before they are used. For practical reasons you must also consent to the use of the photos that you take during the photo activity. These photos will be shared in research reports with researchers, community members, and policy makers. If you are under the age of 18 years, it is necessary that your parent or guardian provide consent for you to participate.

Okay, so I have marked down that you want to participate in sharing sessions with this study. Is there a date/time that would work best for you to review the process of consent before the first session? *Will schedule time/location for consent review.*

For the first session, what days will work for you to attend? What locations are best for you? *Will schedule accordingly.*

Can I please get your name and a number where you can be reached?

Do you have any final questions you would like to ask me?

Please feel free to phone me if you think of any questions before the study.

Thank you very much for your interest and agreeing to participate in the study. I will contact you to remind you of the session the day before it is scheduled. On the day of the study, I will go over the consent form, and there will be time to ask any other questions you have, before the study starts. Thank you again and I look forward to meeting with you!

## APPENDIX D: Facilitation Guides

### Session 1

**[Script enclosed in square brackets is not to be read aloud]**

#### **[Preamble: Introduction]**

Thank-you for agreeing to participate in this sharing session!

During our session today, we will be talking about factors that influence prevention and risk to HIV and Hepatitis C infection. Both of these infections are transmitted through injection drug use and unprotected sex, so questions that we will be talking about will be related to these two topics.

I understand that these are sensitive topics and questions, so I really appreciate your willingness to come and share your opinions today. Please feel free to share as much or as little as you would like. I would like to hear from everyone in the group, so please be sure to add your opinions as we discuss each question. There are no right or wrong answers to the questions that will be asked. If you are telling a story, you are welcome to offer this story from the third person (i.e., using “someone I know” as opposed to “I”).

This information will help us learn about what factors determine prevention and risk of HIV and Hepatitis C infection in your community. Hopefully, this information will be useful for prevention programming and policy in Prince Edward Island, and will also add information to the academic literature.

The first component of this session will involve 9 questions and will last about 1.5 hours. A community member will then guide the remainder of the session, which will be about 30 minutes. If you would like a question to be repeated, just let me know. As you saw on the consent form, you can choose not to answer any question and you can also take a break or stop participating in the discussion at any time.

I look forward to hearing what you all have to say today!

**[Section 1: Conceptualizing Prevention and Risk]**

We are going to start our conversation today by exploring the meaning of prevention and risk in relation to HIV and Hepatitis C.

- 1) *What does HIV and Hepatitis C prevention mean to you? (Alternative: How does HIV and Hepatitis C prevention affect young people in your community?)*
- 2) *What does risk to HIV and Hepatitis C infection mean to you? (Alternative: How does HIV and Hepatitis C risk affect young people in your community?)*

**[Section 2: Proximal Determinants of Risk and Prevention]**

Thank you for your input. Next, we are going to talk about factors in our immediate environment that relate to risk and prevention.

- 1) *Are there pieces in your everyday life that decrease or increase your risk? Would you like to share a story about this?*

*Probes (decrease): Social networks (friends, family, community), cultural events*

*Probes (increase): Physical environment (areas to take drugs, dirty needles), stereotypes*

**[Section 3: Intermediate Determinants of Risk and Prevention]**

- 1) *In your opinion, has the education that you have been provided with about drug use and sexuality increased or decreased your risk? Why? Would you like to share a story about this?*  
*Probes: Culturally appropriate?*
- 2) *In your opinion, do you have sexual health and drug related services that meet your needs? Why? Would you like to share a story about this?*  
*Probes: Condom availability, Needle exchange sites, Testing site*
- 3) *How has involvement in community prevention programs affected your risk? (if involved) Would you like to share a story about this?*  
*Probes: Hep'd Up on Life?*

**[Section 4: Distal Determinants of Risk and Prevention]**

In the next section, we will talk about the influence of traditions, history, and politics on prevention and risk.

- 1) *In your opinion, how do language and traditions play into prevention?  
Would you like to share a story about this?*
- 2) *How do you think history and politics might affect this issue?  
Would you like to share a story about this?*

**[Section 5: Prevention]**

In our last section, we are going to talk about prevention efforts.

- 1) *How do you think this discussion can be applied to prevention in your community? (Alternative: How do you think this discussion can be applied to prevention in other communities?)*



## Session 2

Thank-you for joining us again to participate in this sharing session!

By agreeing to participate in this study, you agreed to participate in all three sharing sessions, including today's session. However, if you would like to end your participation now or at any time, you are free to do so. Do you have any questions about the process of consent that was reviewed?

Today, you will be using the photos that you have taken to tell stories or accounts that you think are applicable to prevention and risk to HIV and HCV. Please feel free to share as much or as little about stories as you would like. If you are telling a story, you are welcome to offer this story from the third person (i.e., using "someone I know" as opposed to "I").

Once again, this information will help us learn about what factors determine prevention and risk of HIV and Hepatitis C infection in your community. Hopefully, this information will be useful for prevention programming and policy in Prince Edward Island, and will also add information to the academic literature.

This session will involve an open discussion for stories and accounts. If you would like to show a picture and/or share an account, simply indicate that you would like to offer your input by raising your hand when you feel most comfortable. If you would like to share more than one story, we will wait until everyone has had a chance to share and then we can hear second stories.

As you saw on the consent form, you can take a break or stop participating in the discussion at any time. Let's begin. I look forward to hearing what you all have to say today!

### **[Theme 1: Proximal determinants]**

We will start by hearing stories about risk and prevention in everyday life. Who would like to begin?

### **[Theme 2: Intermediate determinants]**

Thank you for sharing these stories. Now we will share stories that relate to the systems in our environment. For example, health systems and education systems. Who would like to share stories about these factors?

### **[Theme 3: Distal determinants]**

Thank you for sharing this. Finally, we will hear stories about risk and prevention as they relate to history, and politics. Who would like to begin?

### Session 3

Thank-you for joining us again to participate in this sharing session!

By agreeing to participate in this study, you agreed to participate in all three sharing sessions, including today's session. However, if you would like to end your participation now or at any time, you are free to do so. Do you have any questions about the process of consent that was reviewed?

Today, we will be summarizing the initial findings of the first two sessions. We would like to hear your opinions and thoughts on these findings. This information will help us learn about what factors determine prevention and risk of HIV and Hepatitis C infection in your community. Hopefully, this information will be useful for prevention programming and policy in Prince Edward Island, and will also add information to the academic literature.

Please feel free to share as much or as little as you would like. I would like to hear from everyone in the group, so please be sure to add your opinions as we discuss each question. There are no right or wrong answers to the questions that will be asked. If you are telling a story, you are welcome to offer this story from the third person (i.e., using "someone I know" as opposed to "I").

This session will involve a brief summary of this study's findings so far, followed by 3 questions. This discussion may take up to 1.5-2 hours, or may be shorter. If you would like a question to be repeated, just let me know. As you saw on the consent form, you can choose not to answer any question and you can also take a break or stop participating in the discussion at any time.

I look forward to hearing what you all have to say today!

#### **[Summary of findings]**

#### **[Questions:]**

Now we will talk about these findings. We will discuss whether they represent your experiences, and what can be done with these findings in prevention efforts.

- 1) *Does this summary represent your prevention and risk experiences? Why? Why not?*
- 2) *How can these findings be incorporated into prevention in your community?*
- 3) *What can YOU do with these findings?*

## APPENDIX E: Consent Forms

### **Study Title: Exploring Key Determinants of HIV/HCV Prevention and Risk: Voices of Aboriginal Youth of Prince Edward Island**

Funding: Atlantic Aboriginal Health Research Program

For more information, please contact: Pamela Hudson, Master's student at Dalhousie University. Email: plhudson@mta.ca, phone: (902) 856-1099

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**(Introduction to be read aloud [this is to be used as a guide; points should be clarified in language that is accessible to the participants])**

“Hello [name]:

My name is Pamela Hudson and I am conducting a study as a component of my Master's degree at Dalhousie University in Health Promotion. Dr. Jacqueline Gahagan, a Professor of Health Promotion in the School of Health and Human Performance, is supervising the research. There is also a community advisory committee composed of individuals from across PEI who have guided the development of this study. The purpose of this study is to learn about the factors that influence of HIV and Hepatitis C prevention and risk among Aboriginal youth in PEI.

You are invited to take part in this study. This involves participating in three sharing sessions with other youth from PEI. These sessions will be scheduled according to when participants are available. The second and third sessions also involve a photo taking and photo sharing activity. Taking part in these sessions is voluntary. It is up to you to decide whether or not you will take part in the sharing sessions and you can withdraw your participation at any time.

I will give you a copy of the one-page (double sided) information sheet that describes the sharing sessions and the project. Would you like to be given time to read the sheet or would you like me to review the information sheet with you? [The potential participant will be given time to read the information sheet or the information sheet will be read aloud]. Do you have any questions about these sharing sessions?

Now that we have talked about the sharing sessions and you have had a chance to ask questions, are you interested in taking part in this study?

Information Sheet Page 1:

**Study Title: Exploring Key Determinants of HIV/HCV Prevention and Risk: Voices of Aboriginal Youth of Prince Edward Island**

Funding: Atlantic Aboriginal Health Research Program

For more information, please contact: Pamela Hudson, Master's student at Dalhousie University.

Email: plhudson@mta.ca, phone: (902) 8561099

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**What is the goal of this Study?** The goal of this study is to learn about the factors that influence HIV and Hepatitis C prevention and risk for Aboriginal youth in PEI.

**What is HIV and Hepatitis C?** HIV and Hepatitis C are viruses that can be passed on through unprotected sex with an infected partner and through using injection drugs with unclean needles and/or unclean drug supplies.

**Who can take part in this study?** You can participate in this study if you have lived in PEI (either on or off reserve) for at least 1 year between the ages of 16 and 24, and if you consider yourself to be a First Nations, Inuit, and/or Métis person. You must also be between 16 and 24 years old.

**Who is doing this research?** Pamela Hudson is the researcher for this study. A teacher at Dalhousie University, Dr. Jacqueline Gahagan, is also helping with this project. Also, a university committee and a community committee are helping with this research project. The university committee includes Dr. Debbie Martin and Mrs. Renée Masching. The community advisory committee includes several community members from across PEI.

**What will you be asked to do?** If you choose to participate in this study, you will be invited to take part in 3 sharing sessions. A sharing session is a small group of people meeting to share stories and ideas. The first session will last about 2 hours and the second and third sessions will last around 1.5 hours. All sessions will be audio-recorded and then typed into a computer program. Also, you will be asked to fill out a short survey about yourself, and you will be asked to take part in a photo activity which will take place during the second and third sessions. Because the session will be audio-recorded and typed into a computer program, it is necessary that you give your permission to be audio-recorded. It is also necessary that you allow the researcher to use direct quotes from the sessions. All information that would identify you will be removed from what you say so you cannot be identified. If you ask that the recorder be turned off for a specific comment during the conversation, the recorder will be turned off for that comment. After that comment, the recorder will be turned back on. If you want to end your participation, there is no pressure to continue and you can leave the study at any time. Also, you can request a copy of the results of the study. For practical reasons, it is also necessary that you give your permission for the use of the photos that you take during this project. These photos will be included in reports about this project that will be given to researchers, community members, and policy makers. No photos including identifying information will be included in these reports. If there is a particular photo that you would like to keep to yourself, that is okay.

### **Information Sheet Page 2**

**Are there any risks?** The topics that we will be talking about in the sessions, such as injection drug use and sexual activity, are sensitive topics. Because of this, it is possible that you may become uncomfortable. Before each session begins, you will be offered a card that lists health and drug support services in PEI. If you would like, you can contact these services after our discussions. Also, there will be a community mental health worker available to talk to after the second sharing session. If you would like to talk to this person, a number and email address will be listed for this person on the card that I give to you. If you feel upset and would like to take a break from any of the sessions, or if you would like to end your participation, please tell the session facilitator. There is no pressure to continue and you can exit the study anytime.

**Are there any benefits?** From this study, you may experience positive feelings from having a friendly space to talk about these issues. Your stories and ideas may also be helpful to others by giving new knowledge about HIV and Hepatitis C prevention in PEI. This could be useful for health programs and policies.

**Compensation.** You will receive \$15 for your participation in the first session and \$10 for your participation in the second and third sessions. In total, you will receive \$35. The first session is a bit longer because there is a photography lesson offered by a community member at the end. If you choose to discontinue your participation during any session, you will still receive the full amount of money. You will be asked to sign a paper to make sure that you have received this money. This will take place at the beginning of each session.

**Privacy.** Other youth taking part in the sharing sessions will know who you are and what you have said. You will also know who others are and what others have said. For this reason, it is important that you do not share the identity of other participants or information they have talked about. All information will be stored in a locked place and in a password protected USB key. All materials will be stored for 5 years after publication, and then they will be destroyed. Materials that contain your name, such as this consent form, will be kept separate from other materials. I will not give your name to anyone unless you discuss current abuse of yourself, a child, or adult in need of protection. This includes sexual activity against someone's will and this includes abuse. As a researcher, I have to pass this information to a community worker, Pam O'Neill. This worker will direct you to the right community resources. The information that you share will be typed into a computer program and all information that could be used to identify you will be removed. After identifying information is removed, notes and photos will be shared with community advisors, who are members of the community helping with this project. The people on this committee will have no way of knowing who participated in this study.

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**Questions?** If you have any questions, please contact Pamela Hudson, at (902)856-1099, or at [plhudson@mta.ca](mailto:plhudson@mta.ca). You may also contact the research supervisor, Dr. Jacqueline Gahagan, at (902)494-115, or at [Jacqueline.gahagan@dal.ca](mailto:Jacqueline.gahagan@dal.ca). **Problems or Concerns?** If you have concerns about any part of this study or your involvement, you can contact Catherine Connors, Director of the Dalhousie University's Office of Human Research Ethics Administration at (902) 494-1462, or via email at [Catherine.Connors@dal.ca](mailto:Catherine.Connors@dal.ca). Collect calls are always accepted.

### Signature Form: Consent

#### Study Title: Exploring Key Determinants of HIV/HCV Prevention and Risk: Voices of Aboriginal Youth of Prince Edward Island

Funding: Atlantic Aboriginal Health Research Program

For more information, please contact: Pamela Hudson, Master's student at  
Dalhousie University

Email: plhudson@mta.ca, phone: (902) 856-1099

1. "I have read (or had read to me) and understand the information provided to me about all three sharing sessions and have had all of my questions answered to my satisfaction. By giving my consent, I am agreeing to take part in the three audio-recorded story telling sessions of this study."
  
2. "By giving my consent, I am choosing to allow the information that I share to be used in future reports, publications, and presentations of the data. The stories, information, quotes, and photos that I share will be acknowledged as contributing to the study, but will not be linked with my personal information."

Participant's Signature: \_\_\_\_\_

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Location: \_\_\_\_\_

Statement to receive a copy of the findings of the study:

"I would like a copy of the findings of this study"

Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, the participant's mailing address is:

## Parental Signature Form: Consent for Participants Under 18 Years of Age

### Study Title: Exploring Key Determinants of HIV/HCV Prevention and Risk: Voices of Aboriginal Youth of Prince Edward Island

Funding: Atlantic Aboriginal Health Research Program

For more information, please contact: Pamela Hudson, Master's student at  
Dalhousie University

Email: plhudson@mta.ca, phone: (902) 856-1099

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1. “\_\_\_(Participant's Initials)\_\_\_ understands the information provided to him/her about all three sharing sessions and has had all questions answered to his/her satisfaction. By giving my verbal consent, I am consenting to the participation of \_\_\_(Participant's Initials)\_\_\_ in the three audio-recorded story telling sessions of this study.”
  
2. “By giving my verbal consent, I allow the information shared by \_\_\_(Participant's Initials)\_\_\_ to be used in future reports, publications, and presentations of the data. The stories, information, quotes, and photos shared will be acknowledged as contributing to the study, but will not be linked with the personal information of \_\_\_(Participant's Initials)\_\_\_.”

Signature of Parent/Guardian: \_\_\_\_\_

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Location: \_\_\_\_\_

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Statement to receive a copy of the findings of the study:

“I would like a copy of the findings of this study”

Yes \_\_\_\_\_ No \_\_\_\_\_

If yes the participant's mailing address:

**APPENDIX F: Honorarium Receipt (1)****Receipt of Honorarium**

I, (please print your full name) \_\_\_\_\_, hereby confirm that I have received \$15 from Pamela Hudson for my participation in the first sharing session for the research project entitled: Exploring Key Determinants of HIV/HCV Prevention and Risk: Voices of Aboriginal Youth of Prince Edward Island.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Interviewer

\_\_\_\_\_  
Date



**APPENDIX E: Honorarium Receipt (2)****Receipt of Honorarium**

I, (please print your full name) \_\_\_\_\_, hereby confirm that I have received \$10 from Pamela Hudson for my participation in the second sharing session for the research project entitled: Exploring Key Determinants of HIV/HCV Prevention and Risk: Voices of Aboriginal Youth of Prince Edward Island.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Interviewer

\_\_\_\_\_  
Date

**APPENDIX E: Honorarium Receipt (3)****Receipt of Honorarium**

I, (please print your full name) \_\_\_\_\_, hereby confirm that I have received \$10 from Pamela Hudson for my participation in the third and final sharing session for the research project entitled: Exploring Key Determinants of HIV/HCV Prevention and Risk: Voices of Aboriginal Youth of Prince Edward Island.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Interviewer

\_\_\_\_\_  
Date

### APPENDIX G: Photo-Voice Script

You have been provided with a disposable camera with 24-28 pictures available. You are invited to take pictures with this camera of elements within your environment that might influence prevention or risk of HIV and Hepatitis C. You are invited to take pictures of anything you would like; however, please remember that you cannot take pictures of people. If you would really like to have someone in your picture, please take the picture from a back view in a way for it to be impossible for the person to be identified.

It is also important to note that physical danger could be encountered while taking photos. It is therefore *very* important that you take photos *only* of aspects that you already encounter in your everyday life. It is important that you do not seek out new situations to take pictures of. We would like to see *your* photos from *your* life. There is no need to take photos of anything you would not encounter on a regular, everyday basis.

When we return for our second sharing session, you will be invited to use these pictures to tell stories of accounts that are applicable to prevention and risk. If you would like, you can keep this in mind when taking your pictures.

When you are finished taking pictures, please leave your camera at \_\_\_\_\_ (location specified – all cameras will be stored in a securely locked location). The researcher will collect the cameras and have the photos developed for the second sharing session.

If you would like to stay over the next 30 minutes, a community member will be here to give a brief lesson in photography.

We look forward to seeing your photos!

### **APPENDIX H: Demographic Survey**

This survey is designed to find out more about the participants in this study. This is a very short questionnaire, with only 5 questions. All answers are anonymous, so they cannot be linked to you, and papers will be stored in a secure, confidential location. If you do not feel comfortable answering any of the questions, please leave it blank.

I will read each question aloud and you can write your answer down on the sheet that is before you. If you would like a question to be repeated or would like help writing down answers, please let me know.

- 1) What was your age at your last birthday?
  
- 2) What is your gender?
  
- 3) Do you live on reserve or off reserve?
  
- 4) If you live off reserve, do you live in a city or a town?
  
- 5) How many years of school have you completed?

[This page is to be kept separate from page 1 of the demographic survey]

Would you like your name to be recognized when something is written or presented about this project?

Yes \_\_\_\_\_

No \_\_\_\_\_

If yes, what would you like shared about yourself? (please provide your name and/or any other information that you would like recognized)

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## APPENDIX I

### Support Services for Youth

**Kid's Help Line:** 1-800-668-6868

**Native Council Services:**

**Drug/Alcohol Programs:**

- 1-902-436-7721 (East Prince and Western Queens Counties)
- 1-902-892-2103 (East Queens County)
- 1-902-853-3884 (Prince County)

**Youth Programs:**

- See: [http://www.ncpei.com/programs\\_youthprogram.php](http://www.ncpei.com/programs_youthprogram.php)
- Hep'd Up On Life (HCV prevention program for youth): contact [hepc@ncpei.com](mailto:hepc@ncpei.com)

**Mi'kmaq Confederacy Programs:**

- Family PRIDE program: 1-902-436-5101 ext. 232 OR 1-902-315-1485

**AIDS PEI Services**

- Peer support: 1-902-566-2437 OR [Alana@aidspei.com](mailto:Alana@aidspei.com)
- Office number: 1-902-626-3400

**Community Mental Health Worker:** Available after Session #2  
(number/email provided)