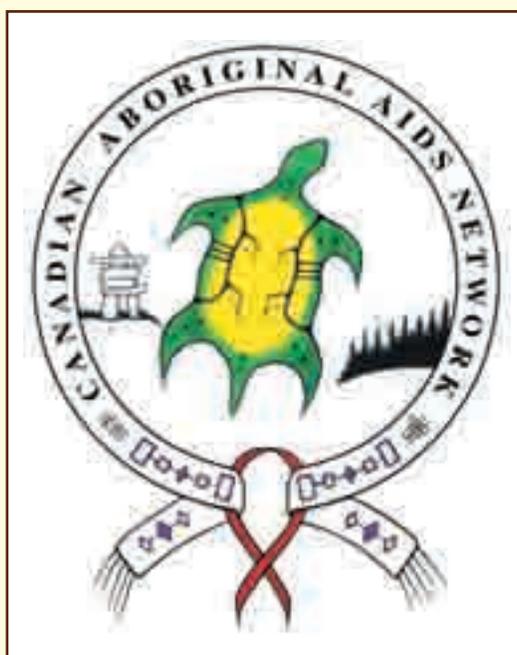
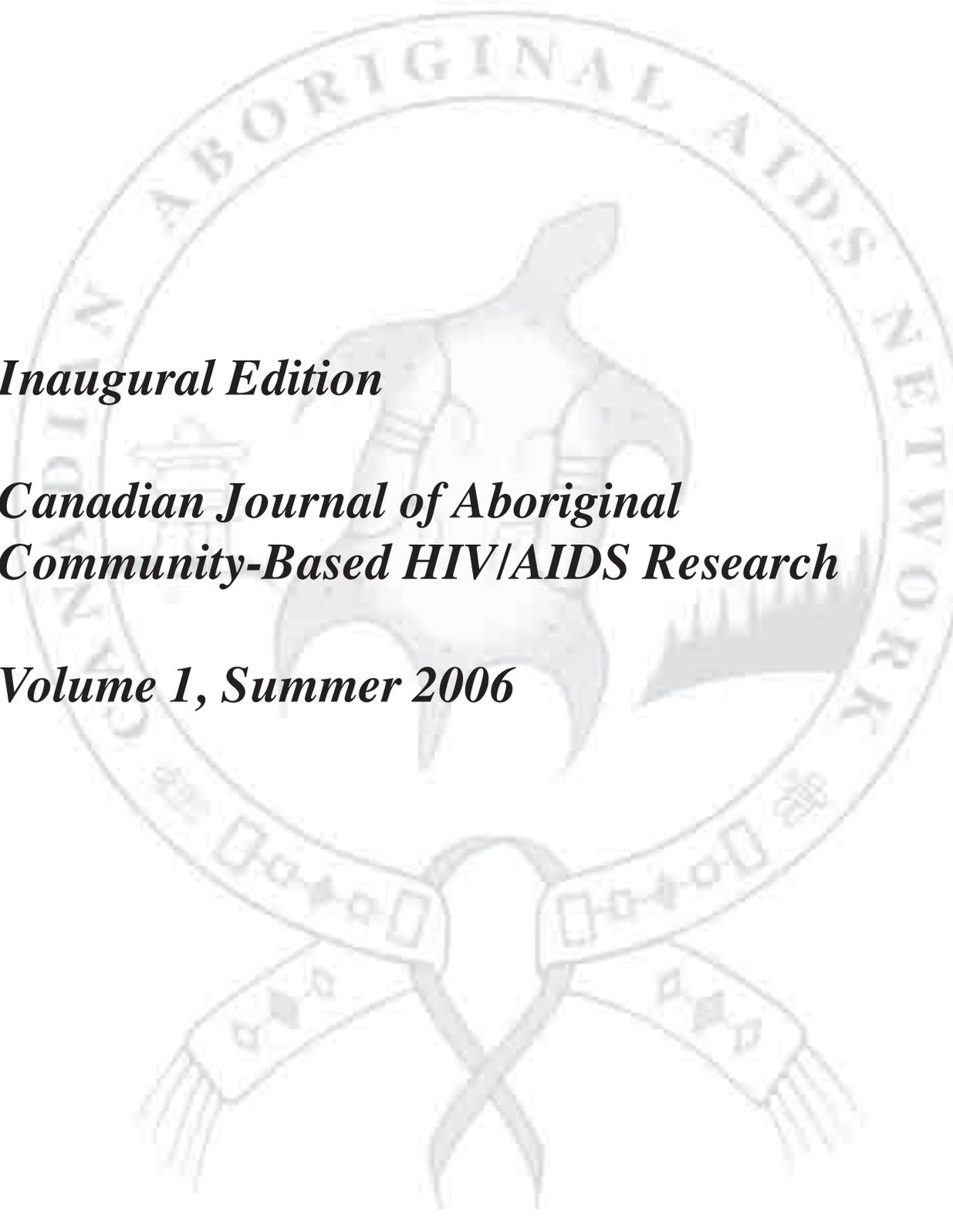


CANADIAN JOURNAL OF ABORIGINAL COMMUNITY-BASED HIV/AIDS RESEARCH

INAUGURAL EDITION • VOLUME 1, SUMMER 2006





Inaugural Edition

***Canadian Journal of Aboriginal
Community-Based HIV/AIDS Research***

Volume 1, Summer 2006

THE CANADIAN ABORIGINAL AIDS NETWORK (CAAN)

Overview

The Canadian Aboriginal AIDS Network is a national, not-for-profit organization:

- Established in 1997
- Represents over 200 member organizations and individuals
- Governed by a National thirteen member Board of Directors
- A four member Executive Board of Directors
- Provides a National forum for members to express needs and concerns
- Ensures access to HIV/AIDS-related services through advocacy
- Provides relevant, accurate and up-to-date HIV/AIDS information

Mission Statement

As a key national voice of a collection of individuals, organizations and provincial/territorial associations, CAAN provides leadership, support and advocacy for Aboriginal people living with and affected by HIV/AIDS. CAAN faces the challenges created by HIV/AIDS in a spirit of wholeness and healing that promotes empowerment, inclusion, and honours the cultural traditions, uniqueness and diversity of all First Nations, Inuit and Métis people regardless of where they reside.

Acknowledgements

The Canadian Aboriginal AIDS Network would like to thank the project steering committee members: Margaret Akan, Randy Jackson, Renee Masching, Jann Ticknor and Art Zoccole for their direction and support throughout the project. In addition, contributions from Yvon Allard and Dina Epale helped to move this project forward.

Production of this document has been made possible through a financial contribution from the Canadian Institutes of Health Research (CIHR). The views expressed herein do not necessarily represent the views of CIHR.

ISBN No. 1-894624-48-3

Canadian Aboriginal AIDS Network
602-251 Bank Street
Ottawa, Ontario, K2P 1X3
Telephone: 1-613-567-1817
Toll-Free: 1-888-285-2226
Internet: www.caan.ca
Email: info@caan.ca

Summer 2006

Canadian Journal of Aboriginal Community-Based HIV/AIDS Research (CJACBR)
Published by the Canadian Aboriginal AIDS Network (CAAN)

Editorial Policies: Purpose and Audience

The CJACBR is an annual on-line and paper journal published by CAAN as a service to its members and anyone with an interest in Aboriginal Community-Based Research.

The CJACBR is a peer-reviewed journal which welcomes contributions from any author. Priority however, may be given to an author of Aboriginal ancestry/background, should manuscripts of comparable quality be available. First consideration will be given to innovative articles covering areas identified as HIV/AIDS research-intensive which demonstrates the use of Aboriginal Community-Based Research (ACBR) methods or philosophy.

Articles published in CJACBR are directed toward several audiences. The primary audience is Aboriginal HIV/AIDS service organizations and Aboriginal people living with HIV/AIDS (APHAs). The CJACBR secondary audiences include community leaders, policy and decision-makers, and anyone with an interest in HIV/AIDS, particularly within Aboriginal populations and communities.

Acknowledgements

CAAN would like to acknowledge the members of the Editorial Peer Review Board. Each member contributed to the development of review policies in addition to contributing to the peer review process.

Editorial Peer Review Board members were:

Harry Adams
Marcel Dubois
Valerie Galley
Charlotte Loppie
Namaste Marsden
LaVerne Monnette
Gabe Saulnier
Mac Saulis
Melanie Rivers

Additional Reviewers:

Additional contributions were offered by Blye Frank, Roda Grey and Marlene Brant Castellano.

CAAN Editors:

Randy Jackson, Renee Masching, and Jann Ticknor

Journal Layout:

Allegra Print & Imaging, 1069 Bank Street, Ottawa

Table of Contents

Introduction	1
Section 1 – Dissemination of Results Findings	3
Life Experiences of Aboriginal Women Living with HIV/AIDS	5
<i>Kim McKay-McNabb</i>	
“River of Life, Rapids of Change”: Understanding HIV Vulnerability among Two-Spirit Youth who Migrate to Toronto	17
<i>Doris O’Brien Teengs and Robb Travers</i>	
Section 2 – Emerging Issues in Aboriginal Community-based HIV/AIDS Research (ACBR)	29
Knowledge Translation and Aboriginal HIV/AIDS Research: Methods at the Margins	31
<i>Renee Masching, Yvon Allard, and Tracey Prentice</i>	
Section 3 – Ownership, Control, Access, and Possession	45
Ethics in Aboriginal Research: Comments on Paradigms, Process and Two Worlds	47
<i>Mike Patterson, Randy Jackson, and Nancy Edwards</i>	
Section 4 – Professional/Personal Development	63
Negotiating Partnership and Ownership in Community-Based Research: Lessons from a Needle Exchange in Montréal	65
<i>Viviane Namaste and Pascal Jauffret</i>	
Call for Papers	75

Introduction

In November 2003, it had become clear that there were few opportunities specific to the Aboriginal HIV/AIDS community to implement the dissemination plans of the research process within which Aboriginal stakeholders had been involved. For this reason, based on a review of the literature and existing resources, the Canadian Aboriginal AIDS Network (CAAN) partnered with community stakeholders and applied for project funding. The overall goal of the project was to enhance dissemination of Aboriginal community-based HIV/AIDS research using a variety of methods.

CAAN recognized that in recent years there had been a notable increase in the scientific examination of the HIV epidemic as it impacts the Aboriginal community. However, while we knew much work was being done, there was not a notable or similar increase in the number of research studies presented in academic journals or at HIV/AIDS academic conferences that highlighted the work of Aboriginal community-based researchers. A review of the literature revealed that virtually no academic journals at this time provide a dedicated venue specific to Canadian Aboriginal community-based HIV/AIDS research.

Almost 3 years later, the inaugural issue of the Canadian Journal of Aboriginal Community-Based HIV/AIDS Research (CJACBR) is complete. The CJACBR has evolved from a desire to assist in the dissemination of research findings into a vehicle to promote and encourage Aboriginal community-based HIV/AIDS research. Great effort has been put into the development of policies to guide journal submissions and peer review processes. Authors from around the world submitted manuscripts and the Editorial Peer Review Board offered carefully considered feedback for each article. The outcome is a journal that strives to balance academic excellence with community relevance in an interesting and engaging format.

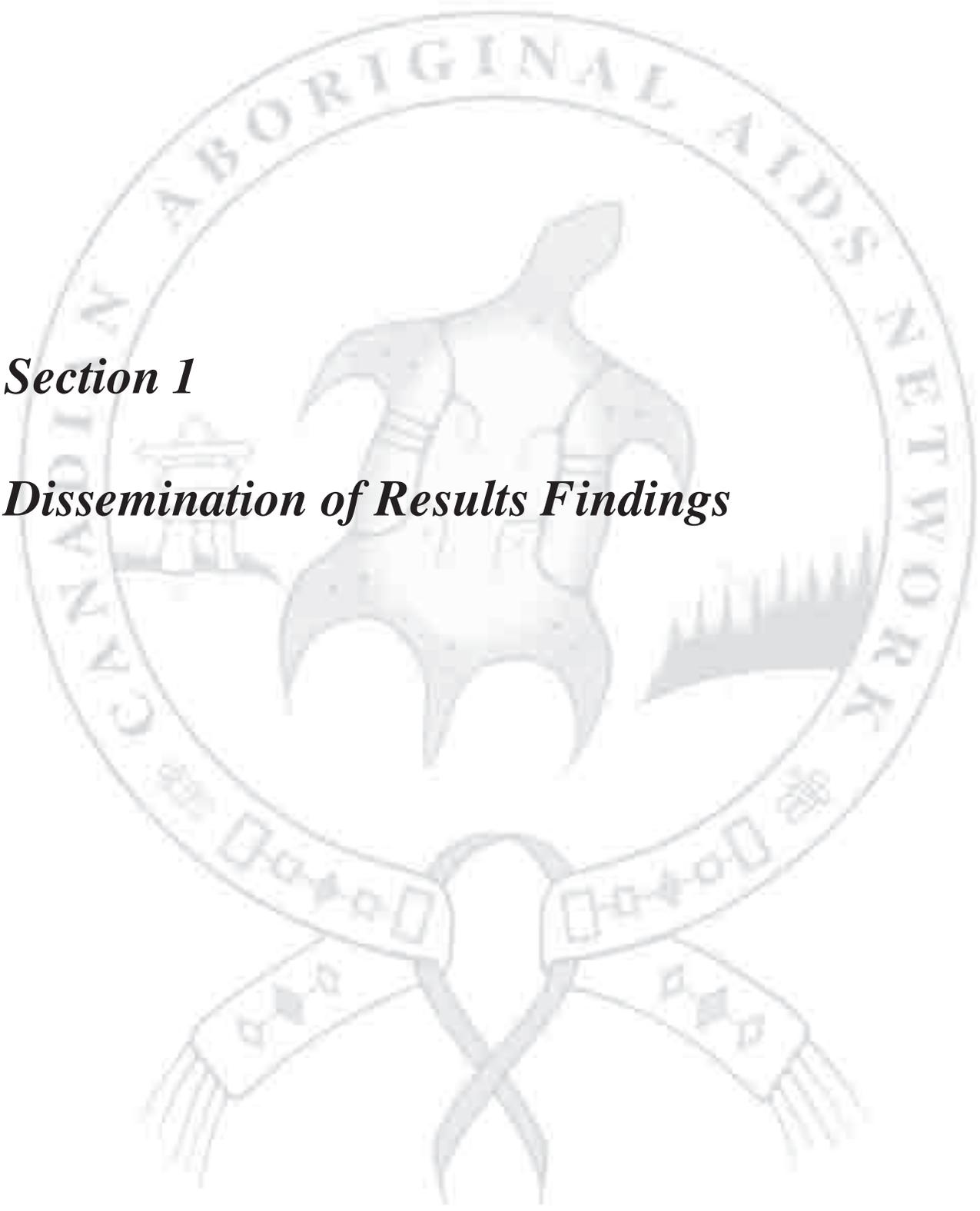
The articles included in this inaugural issue cover a variety of topics. Research findings are presented from two studies that highlight the needs of two spirit youth and women living with or affected by HIV/AIDS. The emerging research concept of Knowledge Translation is explored and presented in the context of Aboriginal HIV/AIDS research. The Principles of Ownership, Control, Access and Possession (OCAP) are linked with research ethics in a practical discussion about academic and community partnerships. The importance of negotiating partnerships is further outlined in the final article which draws on lessons learned to demonstrate the importance of clearly agreeing upon the boundaries of the research process before the work begins.

This is a new medium for sharing insights regarding research processes within the Aboriginal HIV/AIDS movement and a proactive step forward. The publication of this journal fills a significant void and has created opportunities to highlight excellent community-based research. This journal is a foundation to continue sharing ideas, enhance, support and complement research initiatives in all regions and sectors so that Aboriginal people can continue to find innovative ways of taking control of a disease that has taken too much from us.

Kevin Barlow
Executive Director
Canadian Aboriginal AIDS Network

Section 1

Dissemination of Results Findings



Life Experiences of Aboriginal Women Living With HIV/AIDS

Kim McKay-McNabb¹

This research was approved by the University of Regina Ethics Board and followed the guidelines of OCAP. This research was funded in part by the Indigenous People's Health Research Centre (IPHRC) and the Faculty of Graduate Studies and Research at the University of Regina. This article is based on the author's Masters Thesis (2005) entitled: *Life Experiences of Aboriginal Women and HIV/AIDS: A Qualitative Inquiry*.

ACKNOWLEDGEMENTS

I would like to thank the wonderful Aboriginal women who were a part of this research who shared their life experiences of HIV/AIDS. Without their voices this research would not have been possible. I thank them for their dedication to the fight of HIV/AIDS and for sharing their personal experiences to assist our communities to gain a better understanding. I would also like to acknowledge and thank the following agencies and people for their unconditional support; All Nations Hope AIDS Program, AIDS Programs South Saskatchewan and the Canadian Aboriginal AIDS Network. Finally, the contributions that were shared by the women cannot fully be acknowledged in the condensed form of this article. The Masters thesis, *Life Experiences of Aboriginal Women and HIV/AIDS: A Qualitative Inquiry*, is available at the University of Regina at the library in entirety where the Aboriginal women's stories are told in length.

ABSTRACT

HIV/AIDS is rapidly becoming an epidemic in Aboriginal communities. There is currently a lack of research investigating the factors influencing the spread of this illness among Aboriginal individuals. Particularly, research is lacking in the area of Aboriginal women and HIV/AIDS. The goal of this study is to contribute qualitative data to our understanding of how Aboriginal women have experienced the impact of HIV/AIDS. Eight Aboriginal women who are *infected with HIV* (n=4) or *affected by* (n=4) HIV participated in qualitative open-ended interviews to generate a propositional theory which described the women's journey on *the path to healing*. Grounded theory methods were used to discover the broad themes. The participants described their journey on the path to healing as a process of integrating acceptance, risk factors and everyday challenges, support, and developing new identities as Aboriginal women living with HIV/AIDS or as individuals affected by HIV. The participants' journeys ("*walking on the path of healing*") are depicted on the medicine wheel – a traditional model of health and healing which represents the stages one must pass through in a cyclical manner. The participants of this study drew strength and personal understanding from the medicine wheel – they could understand their own experience as it was reflected in the model. Even though the women were at a variety of healing stages, the model held meaning for each woman. Through the gift of understanding provided by the medicine wheel, the participants found the strength to begin and continue walking on their path of healing.

¹University of Regina, kim.mcnabb@uregina.ca

INTRODUCTION

Aboriginal² women have been identified as having one of the highest rates of HIV infection in Canada. Aboriginal women are significantly impacted as they represent nearly half (45.1%) of all positive HIV test reports among Aboriginal Peoples, compared with non-Aboriginal women who represent 19.5% of reports among non-Aboriginal Peoples (Health Canada, 2004). Today, Aboriginal women face a number of health obstacles and challenges which relate to a number of determinants of health. Poverty, addictions, sexually transmitted infections, and limited access to or use of health care services all contribute to their health experience (Health Canada).

Cruikshank (1990) discusses the value of expressive forms like storytelling to generate information and initiate social, cultural, and economic change. In this article Aboriginal women share their stories and life experiences of HIV/AIDS, and are candid about the challenges and obstacles they experience as they walk on their journey of healing while living with or being affected by HIV/AIDS. This research is meant to assist the Aboriginal women who participated to share their life experiences in their own words, to give voice to their experiences, and to contribute to the sparse literature about Aboriginal women and living with HIV/AIDS.

HIV/AIDS AND ABORIGINAL WOMEN IN CANADA

Aboriginal women in Canada are over represented in HIV/AIDS statistics (Prentice, 2004). The rate of new HIV infections among Aboriginal women in Canada is on the rise and has been steadily increasing to epidemic proportions for Aboriginal women over the past two decades (Canadian Aboriginal AIDS Network, 2003; 2005; Mill, 2000). Available statistics on the disease do not indicate the actual number of infected Aboriginal women as many cases go unreported (Mill, 2000). Aboriginal HIV cases are underestimated because of under-reporting for ethnicity, variations in reporting ethnicity within and between provinces, delays in reporting, and misclassifications in ethnic status (Health Canada, 1999).

Aboriginal women in Canada are affected by HIV/AIDS at a higher rate than women of other ethnic groups. These higher rates are explained in the literature as being linked to marginalization, gender, poverty, identity and colonization (Bourassa, McKay-McNabb, & Hampton, 2004). Previous researchers have found that race, culture, gender, and ethnicity are important determinants of health, which are often interrelated (Armaratunga, 2002). As well, Tanenberg (2003) states that the traditional role that Aboriginal women played in their communities has been altered since contact with Europeans. One of the contemporary results of this impact is that Aboriginal women are at greater risk for HIV, and are becoming infected with and affected by HIV/AIDS at alarming rates.

Bourassa, McKay-McNabb, and Hampton (2004) described how sexism, racism, and colonialism have joined to create levels of systematic oppression that differentially affected specific Aboriginal groups, and men and women within these groups. Bourassa et al. discuss how Euro-Canadian legislation, which attempts to define Aboriginal identity, does not take into account the diversity within Aboriginal communities. The *Indian Act* which was officially passed in Canada in 1876 defined what Indian identity and 'Indianness' would mean from that point forward in history. The injustice and ramifications of the sexist specification inherent in this legislation of the *Indian Act* were more severe for Aboriginal women than men. This injustice continues to have implications to this day, and impacts how Aboriginal women are able to live their lives and the choices they have available – limited choices may contribute to the increased numbers of Aboriginal women being infected or affected by HIV/AIDS.

² The term Aboriginal has been defined by Indian and Northern Affairs Canada as: descendants of the original inhabitants of North America (INAC, 1999). In 1982, the *Canadian Constitution* Section 35(2) defined Aboriginal peoples as being three groups: Indian, Inuit and Métis (Department of Justice Canada, 1982). In this study Aboriginal is defined as individuals who self-describe as First Nations (status/non-status), Inuit and Métis.

DEFINITIONS

Terminology to describe Aboriginal women living with HIV is relatively new to the HIV community and to researchers. It was challenging to find a term that would represent the Aboriginal women who participated in this study. This challenge reflects the changing landscape in the literature that contains varying definitions of groups living with HIV/AIDS, and also reflects the importance for any people with a history of oppression to define their own reality. With some guidance from the Canadian Aboriginal AIDS Network (CAAN), I decided to use a term recently introduced in Jackson's (2005) document, *Aboriginal Women with HIV/AIDS: Care, Treatment and Support Issues*. The term "Aboriginal Person Living with HIV/AIDS" (APHA) has been used for about nine years by Aboriginal groups to identify and reinforce the fact that the experience of APHAs is unique and requires particular attention. The history of Aboriginal women and their relationship to the health system suggests that a term describing this population should be generated from within the Aboriginal community -- a way of claiming their own reality. To address this, Jackson expanded on the APHA term to include Aboriginal women living with HIV/AIDS (AWHAs), suggesting that the experience of Aboriginal women is unique in its own right. The term AWAHA appears to be an appropriate term that incorporates the uniqueness of "Aboriginal" and "women" and has been adopted for use in this research to describe the Aboriginal women who have participated in this study.

There are few definitions in the literature describing Aboriginal women *affected* by HIV. Again, it was a challenge to find a definition that would describe Aboriginal women who are affected by HIV through a family member living with HIV, a community member having HIV, or working in a front-line capacity with an Aboriginal AIDS Service Organization (AASO)/AIDS service Organization (ASO). One study specifically addressed this issue and defined Aboriginal women who are caring for AWHAs as *caregivers* (Ship & Norton, 2001); however, the participants in my study were not always the caregiver, so this definition would not work for my purposes. The term *affected* has been used in this study to refer to any Aboriginal woman who is close to an Aboriginal person living with HIV/AIDS.

METHODOLOGY

Grounded theory methodology (Strauss & Corbin, 1998) was used to explore how AWHAs and women affected by HIV/AIDS experience the illness. This method is well-suited for research with Aboriginal people as oral stories are part of the history and traditions of Aboriginal communities, where storytelling was a means of sharing and transferring information (Mill, 1997). Furthermore, qualitative methods have been shown to be useful when exploring areas about which little is known, such as Aboriginal women's experiences with HIV/AIDS (Strauss & Corbin, 1998). This was also an appropriate choice of methodology as it facilitates open-ended questioning about lived experiences.

PARTICIPANTS

Eight Aboriginal women ranging in age from 25 to 50 years participated in this study. Purposive sampling methods were used to recruit participants (Berg 1995). Inclusion criteria for participating in the study were: (1) Aboriginal women living with HIV/AIDS (AWHAs); (2) Aboriginal women affected by HIV/AIDS, which consisted of a family or community member living with HIV/AIDS or an AASO/ASO frontline service provider. Four AWHAs and four Aboriginal women affected by HIV/AIDS participated in this study.

Pseudonyms were chosen for each participant from a baby name generator web site (www.popularbabynames.com) which included a section for Aboriginal names. The names were chosen to represent the Aboriginal women in this study and to protect their identities. Confidentiality for the participants was particularly important because HIV/AIDS is a highly stigmatized illness, especially within the Aboriginal community. The pseudonyms and some demographic information of the participants are presented in Table 1.0 and Table 2.0.

RECRUITMENT PROCESS

Potential participants were recruited through AASOs and ASOs in Regina that provide support services for AWHAs and those affected by HIV/AIDS. All Nations Hope AIDS Network, AIDS Program South Saskatchewan, and community-based centres in Regina assisted in the recruiting process in a number of ways: agencies posted notices describing the study within their offices, front-line service providers hand-delivered information posters to potential participants, and introduced me to potential participants at various HIV/AIDS functions in our community.

Working within the agencies as a volunteer, attending numerous HIV/AIDS conferences and gatherings, as well as work on previous research projects facilitated trust building with potential participants, which helped facilitate the recruitment process. In addition, being an Aboriginal woman who has personally experienced the affects of HIV/AIDS with an older sister who lived with HIV/AIDS for a number of years assisted in the recruitment process – participants knew I understood personally and culturally.

Each participant filled out a background information form. Interviews were approximately sixty to ninety minutes in length and were conducted at All Nations Hope AIDS Network, AIDS Program South Saskatchewan, or a participant’s place of residence. Six out of the eight participants requested interviews in their homes because they wanted to ensure their identities were kept confidential.

The AWHAs and the Aboriginal women affected by HIV/AIDS in this study are from First Nations in Saskatchewan, Manitoba, and British Columbia. However, many of the women reside in urban centers. Many are mothers and grandmothers. Some have strong connections to their families and communities. Others do not have this support. A number of the women have a connection to their culture and traditional ways, while others do not. Each of the women has an individual experience with HIV/AIDS, which demonstrates the diversity and individuality of the Aboriginal women’s’ experiences.

TABLE 1.0
ABORIGINAL WOMEN LIVING WITH HIV/AIDS (AWHAs)

<i>Pseudonym:</i> Meaning	Aiyana : Eternal bloom	Honovi : Strong Deer	Gaho: Mother	Mahala: Woman - Powerful
Age	25	42	45	26
Marital Status	Common-Law	Common-Law	Single	Divorced
Children	4	5	1	3
Experienced a pregnancy while living with HIV	Yes. Four pregnancies & all children have tested negative for HIV	No	No	Yes. One pregnancy and child has tested negative for HIV.
Ages of Children	4, 2-2, 1	25,23,19,17, &13	22	16 months 4, 9
Years Infected by Illness	6 years	11 years	4 years	1 ½ years

TABLE 2.0
ABORIGINAL WOMEN AFFECTED BY HIV/AIDS

<i>Pseudonym:</i> Meaning	Chloe: (Intelligent, wise, serious)	Ituha : (strong, sturdy)	Zonta : (trustworthy)	Natane : (sister)
Age	47	58	40	36
Marital Status	divorced	single	common-law	divorced
Children	3	2 : one daughter one son (son deceased) 5 grandchildren	2 daughters one son	4 daughters
Ages of Children		Daughter 28 grandchildren range in age from 12 - 3	20, 17 & 12	18,17,9 and five months
Years Affected by Illness	Over 20 years with her brother	8 years with her son	9 years as a support worker	Five years with her sister

INTERVIEWS

Qualitative, semi-structured interviews were used, which are considered a useful tool for discovering information about under-researched issues (Rubin & Rubin, 1995). Interview questions were designed to allow participants the freedom to share their life experiences with HIV/AIDS. Open-ended questions were asked in order to encourage participants to describe their unique experiences of HIV/AIDS. The questions were adapted and changed as the research progressed to accommodate differences in the participant's stories and to create an open environment in which they could express their individual life experiences.

Consistent with grounded theory, joint data collection and analysis was employed (Strauss & Corbin, 1998). Interview data were individually transcribed and the transcripts were entered into the qualitative software package NVivo version 6.0 (Richards, 1999). Strauss and Corbin (1998) recommend three levels of coding: open, axial, and selective coding and this process guided the data analysis. Throughout data analysis, the constant comparative method described by Strauss and Corbin was used to analyze the data and occurred until theoretical saturation was achieved. Using NVivo computer software enhanced the ability to objectively compare stories at this stage of coding. Quotes that best illustrate the emerging theory were chosen and provide the "grounding" for the themes. Through this process the data is transformed into various themes and a propositional theory emerges to describe the life experiences of AWHAs and Aboriginal women affected by HIV/AIDS.

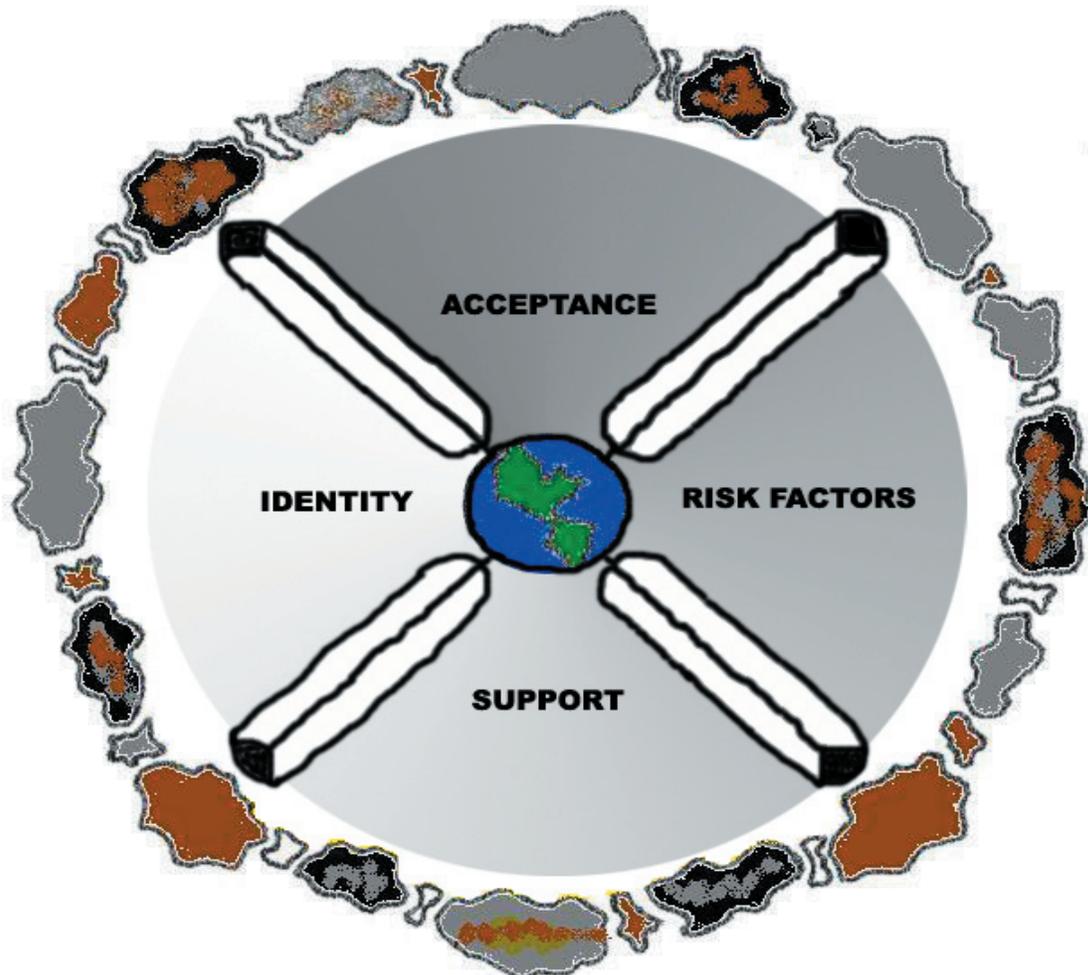
CULTURAL APPROACH

There were a number of traditional and cultural aspects that were introduced to the Aboriginal women by the researcher to assist with the interview process. Participants were given the option of smudging before and after

the interview if they chose to, as well, if the participant requested a particular traditional ceremony or approach to the interview, it was carried through respectfully. For example, Mahala requested that she have her feather present and that she burn her own sweet grass. Also, the participants were presented with a selection of rocks at the beginning of each interview and were encouraged to choose a rock or two to handhold for support through the interview process, if they were interested. They were advised that they could share their stories while holding the rocks; afterwards they could choose to keep the rocks with them or the researcher would take the rocks to an upcoming sweat where the rocks would be cleansed in the sweat and the womens' stories would be released back to the Creator. Many participants chose two rocks and returned one to be cleaned through the sweat. Many of the women kept the other rock with them and took it home once the interview was completed. This process was truly an important aspect to the research methodology as it represented their connection to mother earth and traditional aspects of First Nations Culture. Some women commented that it was an important aspect to them and it added meaning to the interview process.

RESULTS: THE HEALING JOURNEY

The propositional theory generated from the data analysis suggests that Aboriginal women “walk on a path to healing”; the steps in the journey include acceptance, risk factors, support, and identity (see Model 1.0). As the participants walk on this path to healing they have different experiences and, therefore, are at different steps in this journey. The path that they are walking is analogous to the medicine wheel model in that each woman’s journey takes them through steps that integrate their personal experiences into a holistic sense of identity.



Model 1.0: Medicine Wheel: Walk on a Path to Healing

At the first step, an Aboriginal woman is accepting her HIV illness and embracing it as a part of her identity. During the second step, she may be confronted with numerous risk factors and challenges. The third step involves establishing and walking with a network of support from numerous sources: families; front line support workers, urban community, First Nations communities, conferences, and women's retreats and gatherings. The support takes numerous forms which may include traditional support, spiritual support, informational support, and most importantly unconditional support. At the fourth step, the Aboriginal women have passed through their journey of acceptance, have identified with living positive or being affected by HIV, and are now embracing their new identity. As they journey on this path they may spend more time at one part of the path, skip over a step on the path, or return back to a step. The journey is not a linear process of stages where each stage occurs one after the other building on the previous; rather, it is a process that varies for each individual woman. Although the journey is unique to each woman, there are shared experiences along the path.

The participants' journeys ("walking on the path of healing") are depicted on the medicine wheel, which is a holistic approach to understanding that each of us as individuals has our own medicine wheel, no two are the same, and we each walk on our own path (see Model 1.0). The journey includes holistic elements of the medicine wheel which are the spiritual, mental, physical and emotional. Many of the Aboriginal women who participated in this research walk on the path that comes from a place of pain and abuse; they come to a moment of realization; then they arrive at a crossroads where they may decide to follow the medicine wheel in their journey or wait for the time to be right when they are willing to step on to the path of healing.

CORE CATEGORIES

Four core categories emerged from data analysis. The most salient core category for the Aboriginal women participating in this study was *acceptance*, followed by the categories of *risk factors and challenges*, *support*, and *family*. Quotations from AWHAs and participants who are affected by HIV/AIDS are included to highlight and contextualize the core categories. Analysis of interviews suggested that the experience for these two groups were similar in that they could be described within the same core categories.

ACCEPTANCE

All participants stated that they experienced a lack of acceptance of people living with HIV/AIDS. This lack of acceptance comes from broad society, but more painfully may come from their family members, and from members of their Aboriginal communities. Participants agreed that unconditional acceptance from individuals who are important to them is essential to their healing.

All of the Aboriginal women associated a multitude of feelings with coming to terms with their illness, a family member's illness, or being in an AASO/ASO. Their healing journeys are at different steps on the path to healing and they are at different places dealing with the emotions that accompany the path to acceptance, which is a part of their first step on the path to healing. Gaho describes the emotional turmoil she experienced while she was coming to terms with accepting her illness. She describes her initial feelings after being told that she was HIV positive and reflects on where she is now in the following way:

Depression...It was like I was walking in a nightmare for about the first six months. I was numb. Like, I was walking around alive, but yet my mind was dead and numb. All I could just like think of was the virus. It was so hard. That and the battle with the depression part. I was just thought my life was going to totally end right there. And I am ashamed. I was ashamed to know that I was sick with that illness. Alone. I really felt that I was alone. That nobody knew what I was going through. Anger. Anger at my partner. Angry at myself. For living the life that did give me that disease.

That's what it was at the beginning. You know, I thought it was like instant death. I've been there. And as I begin to read books, research it myself that I realized that I could live years and years.

After many years walking her path, Gaho now speaks out at numerous gatherings in Saskatchewan about HIV, informs her family and Aboriginal communities about HIV through learning as much as she can about HIV, and educates others in order to battle this illness. Her acceptance and understanding of her illness has equipped her with the tools she needs to assist her on her path to healing.

Mahala has just begun her journey and she shared what it is like for her to be newly diagnosed. Her journey has included numerous hardships to overcome before she will be prepared to accept what it means for her. Mahala describes the everyday struggles that she endures while facing this illness which includes high risk situations, lack of support, and not being ready to accept her new identity. She also describes that she still relies on her addictions to assist to cope with HIV/AIDS:

Living with it now is a struggle, even though I am in the beginning of the HIV stage. Yes. But it is a struggle for me to go to my doctors every three months just to get blood drawn. Worried about what my next CD 4 and my viral load is going to say. And um, it's scary to me to just watch as the CD 4 drops every time I go in for a visit. And, it's also scary just to see the rise in virals of HIV in your system. Thousands. And um, whether it is starting next. I do know that there are lots of side effects to these meds and they don't make you feel all that great. I just don't like being sick. Usually when I get sick, I cope with it by doing heroin, morphine. It helps me cope with the pain. I also find it hard being HIV positive living on a reserve. So isolated. Um, especially in a province where I have no family and I don't know anybody. The only people I got is my husband and my daughter. And even that doesn't help me all the time.

Mahala is in the beginning steps of her healing journey and accepting her new life; and she is determined to make some healthy choices in her life that will begin her journey on the path to healing. Once she begins to understand that, she needs to step on the path to healing, tackle the addictions, gain support, and find peace with her new identity.

All participants experienced numerous hardships and intense emotional turmoil as they come to accept their HIV status. It is important to note that not all women are on the same path and that each AWhA and woman affected by HIV/AIDS shared where they are in their journey in order to share their story and assist other women to begin their journey.

RISK FACTORS

Aboriginal individuals who live within Aboriginal communities often continue to experience high risk situations when they are trying to survive everyday life. The participants shared their diverse experiences of living in both urban and rural settings, which demonstrates the diversity of our Aboriginal communities. A few of the Aboriginal women describe what it was like within their First Nations communities, which is a subjective, individual experience and does not represent a generalization to all First Nation communities. Poverty, addictions, and prostitution are a part of many communities; these are high risk activities that expose Aboriginal women to HIV/AIDS. Participants describe how they are exposed to high risk activities on a daily basis. Most participants will take the time to educate others and share their experiences about living with HIV/AIDS to try and prevent others from contracting the disease. Gaho describes risk factors that she experienced within the urban Aboriginal community, and that she faces on a daily basis:

Sometimes I know that they don't practice safe sex. And this girl, I have a few nieces and different kids that I know and they are on the street, too. Whether they are using condoms or not. I always stress the fact that they should use condoms. And people that I know that are injecting, I tell them to use clean rigs.

Gaho is on her path to healing; she has experienced street life first hand and would like to prevent others from being exposed to what she has endured and now lives with - HIV/AIDS. She shares what it was like for her in

order to educate and provide awareness to her family and members of Aboriginal communities. She shares her story hoping that she may prevent others in the Aboriginal community from becoming infected.

Participants who are affected by HIV indicated that they witness high risk situations within their Aboriginal communities. It is essential to understand that while high risk situations are a part of our urban and rural Aboriginal communities participants felt individuals can decide to take another path involving less risk. Each participant indicated that there are choices in life about which path to take; each choice is up to the individual. If the path is unhealthy the risk increases, however the path can always be changed to lead to a healthy lifestyle.

SUPPORT

The Aboriginal women shared a need to be supported by their families unconditionally. They look primarily to their families as their first line of support and most important source of support. This support impacts their overall well being. For example, Aiyana indicates how her family supports her unconditionally regardless of her HIV status:

From my immediate family. Um, I guess they have always been there. I got to say for my kids. They love me to death no matter what. And that's the biggest support of them all. Um, and as for my sisters, uh, they tend to forget that I am positive and you know they treat me as if I were never sick and that I am never going to die. And in a way that's good and then again its bad cause you know, I don't want to disappoint them because they are always so proud of me. And you know they listen to me. Yes. And I try and keep... And they understand. They are not all scary about HIV and AIDS and even Hepatitis C. They understand eh. They are really good people.

However, participants indicate that not all Aboriginal families provide this support to their family members once they learn about their HIV positive status. When the support is not there women indicate that they struggle with moving forward with their healing journey. Some First Nations communities are not ready to begin to understand how this epidemic is going to affect their communities. For example, Natane describes how she would like to see her First Nation community begin on their healing path and accept and embrace the Aboriginal women living with HIV/ AIDS:

No, not the reserve because it's so much politics out there. You know, back home on my reserve, like I'm not speaking about everybody's. I know that there are a few people there who are infected. But there is no help out there. That's what I would like to see.

At this point in time she knows that her First Nations community is not close to providing the support and acceptance that Aboriginal women need when living with HIV/AIDS.

IDENTITY

Some of the Aboriginal women have embraced their new identities as Aboriginal women living with HIV/AIDS. Most of them have endured the first few steps with perseverance and today they are proud of who they are. They indicate that their new identities have evolved over time as they began to accept and understand the tremendous journey they would take in their path to healing with HIV/AIDS. Some participants have endured hardships and persevered through high risk lifestyles, sought the support they needed and have begun to develop their new identities as Aboriginal women living with HIV/AIDS. Other participants are still struggling to deal with the risk factors that are a part of their everyday lives. It is important to understand that the Aboriginal women who are affected by HIV/AIDS go through developing new identities as well when they have a family member or loved one living with HIV/AIDS. Each of the Aboriginal women interviewed shared experiences unique to their lives and their individual stages of identity that truly revealed what it was like to walk on the path to healing with HIV/AIDS.

Zonta experienced a few tragic deaths while working as an Aboriginal AIDS service provider which took a toll on her path to healing. She describes the emotional affects that this had on her, to a point where she decided to take a leave of absence from her job to recover:

I kinda blamed myself after, because after the first woman who I met committed suicide, there was another person after that who committed suicide. And it was just like one after the other. And I had no support. I tried to take it to talk to my boss about it but I couldn't because it was just, it was all me internalizing the trust.

At this point Zonta felt she was alone and did not feel she had the supports needed to continue to provide support to the AWHAs. She needed to take time off and seek the traditional supports through ceremony that assist her today to continue to provide support as a front line service provider:

And having to see others. I said okay, it's not my fault, I can't take on all of this responsibility. And be that I can only pray for them, so uh, that's why I go to sweats as much as I can because it takes all of that away from me. Ceremonial.

As she continues to seek the traditional support to assist her with her work with AWHAs and Aboriginal women affected by HIV, she has developed a new identity that has assisted her to become the woman she is today. Her new identity was developed through years of front-line work with people living with HIV and she has become a stronger person because of the work that she does.

DISCUSSION

Due to the lack of research with AWHAs, it is important to understand that the participants in this research describe the range of risk factors that they encounter in day-to-day living. Poverty accounts for higher all-cause morbidity and mortality among people at the lowest socioeconomic levels (Amaro et al., 1995). In a study by DeMarco and Johnsen (2003) women clients in inner city Boston who were accessing health support services raised concerns to their health care providers that their needs were unique and complex, compared to male clients. The women described their struggles during contact appointments, including isolation, low-self-esteem, family/child concerns, housing, violence, chemical addictions, and different physical side effects from antiviral medications and paralyzing uncertainty. Many of the participants in this study describe similar struggles to those expressed by the women in Boston. In this research, Mahala and Honovi both stated that addictions had an impact on their lives acting as a means to numb the reality of living with HIV/AIDS. Their high risk lifestyles have not allowed them to step any further on the path to healing.

Binder (2004) describes the layers and layers of discrimination that a woman feels because of her sex, being Aboriginal, an intravenous drug user, poor, homeless or under housed and unemployed. Studies that have been conducted in Vancouver's East Side indicate the incidence of HIV among female drug users is 40% higher than male drug users (Craib, K.J.P. et al, 2003). It is important to note that two participants in this research would like to let go of the addiction, yet with the lack of supportive programs to assist them in Saskatchewan, they are still in the addictions phase of their journey. Binder described the range of social problems which First Nations people experience in Canada, all of which contribute to HIV infection, and specifically discusses the social problems that Aboriginal women face, including alcoholism, substance use, high suicide rates, violence against women, and family violence.

To assist Aboriginal women on their path to healing there need to be more support programs designed to meet the needs of the Aboriginal women. Cultural/ traditional supports also need to be more accessible and in place in both urban and rural communities because at this time there are not enough programs and resources for Aboriginal women to access to meet their needs. Many Aboriginal women do not know they are infected with HIV and may go undiagnosed until their partner tests positive or they become pregnant or very sick. Perhaps it would be beneficial in the future to communicate just how important testing can be to assist with the healing process and a healthy well being.

CONCLUSION

Aboriginal women develop a new identity as an AWA or being affected by HIV/AIDS. When the women have persevered through high risk situations, surpassed some everyday challenges, received supports then they reach a place where they have come to terms with their new identity. The identity that each woman develops evolves over time. Some women are still on the path to healing at the first part of their journey with acceptance, while others have achieved coming full circle and developed a new identity. Their new identity came from their journey of acceptance of HIV/AIDS and most of the women described how it changed their lives. Some express that if they did not experience this illness, they may not be here today because of the high risk lifestyles that they had lived. Many of the Aboriginal women who participated in this study have developed a new identity and are now proactive in the fight against HIV/AIDS.

A major theme that emerged from the interviews was the participants' need and desire to be on their path to healing while accepting their illness of HIV. If they were on this path, they were able to embrace their journey and continue with their healing process. The propositional theory which emerged describes the need for ways to address the everyday risk factors, seek support, and develop a new identity. The Aboriginal women's acceptance of HIV is truly an individual journey of healing.

REFERENCES

- All Nations Hope. (2002). Personal Correspondence, Regina, Saskatchewan.
- Amaro, H., Jenkins, W., Kunitz, S. Levy, J., Mixon, M. & Yu, E. (1995). Panel I: Epidemiology of minority health. *Health Psychology, 14*(7), 592-600.
- Berg, B. (1995). *Qualitative research methods for the social sciences* (2nd ed). Needham Heights, MA: Allyn & Bacon.
- Binder, L. (2004). Living with HIV. *Canadian Woman Studies, 24*(1), 55-58.
- Bourassa, C., McKay-McNabb, K. & Hampton, M. (2004). Racism, sexism and colonialism: The impact on the health of Aboriginal women in Canada. *Canadian Woman Studies, 24*(1), 23-29.
- Canadian Aboriginal AIDS Network. (2005). *Lives lived with HIV/AIDS: Speaking in public from the perspective of Canadian Aboriginal peoples*. Ottawa, ON: Canadian Aboriginal AIDS Network.
- Canadian Aboriginal AIDS Network. (2003). *Strengthening the ties – strengthening communities: An Aboriginal strategy on HIV/AIDS in Canada for First Nations, Inuit and Métis People*. Ottawa, ON: Canadian Aboriginal AIDS Network.
- Craib, K.J.P., Spittal, P. M., Wood, E., Laliberte, N., Hogg, R. S., Li, K., Heath, K., Tyndall, M. W., O'Shughnessy, M. and Schechter, M.T. (2003). Risk factors for elevated HIV incidence among Aboriginal injection drug users in Vancouver. *Canadian Medical Association Journal, 168*,1-6.
- Cruikshank, J. (1990). *Life lived like a story: Life stories of three Yukon native Elders*. Lincoln, NE: University of Nebraska Press.
- DeMarco, R., & Johnsen, C. (2003). Taking action in communities: Women living with HIV/AIDS lead the way. *Journal of Community Health Nursing, 20*(1), 51-62.
- Department of Justice Canada. (1982). *The Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11. Ottawa, ON: Department of Justice Canada.

- Gahagan, J., & Loppie, C. (2001) Counting pills or counting on pills: What HIV+ women have to say about antiretroviral therapy. *Canadian Women Studies*, 21(2), 118-123.
- Health Canada. (2004). *HIV/AIDS EPI updates, May 2004*. Ottawa, ON: Surveillance and Risk Assessment Divisions, Centre for Infectious Disease Prevention and Control, Health Canada.
- Health Canada. (1999). *Aboriginal peoples and the AIDS epidemic in Canada, an update: December 1999*. Ottawa, ON: Health Canada and Canadian Aboriginal AIDS Network.
- Indian and Northern Affairs Canada (1999). *Aboriginal awareness workshop: Guide to understanding Aboriginal cultures in Canada*. Ottawa, ON: Indian and Northern Affairs Canada.
- Jackson, R. (2005). *Aboriginal women living with HIV/AIDS: Care, treatment and support issues*. Ottawa, ON: Canadian Aboriginal AIDS Network.
- Mill, J. (2000). Describing an explanatory model of HIV illness among aboriginal women. *Holistic Nursing Practice*, 15(1), 42-44.
- Mill, J. (1997). HIV risk behaviours become survival techniques for aboriginal women. *Western Journal of Nursing Research*, 19(4), 466-490.
- Prentice, T. (2004). *HIV/AIDS and Aboriginal women, children and families*. Ottawa, ON: Canadian Aboriginal AIDS Network.
- Richards, L. (1999). *Using NVivo in qualitative research*. London: Sage Publications.
- Rubin, H., & Rubin, I. (1995). *The art of hearing data*. Thousand Oaks, CA: Sage Publications.
- Ship, S. J., & Norton, L. (2001). HIV/AIDS and Aboriginal women in Canada. *Canadian Women Studies*. 21(2), 25-31.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed). Thousand Oaks, CA: Sage Publications

“River of Life, Rapids of Change”: Understanding HIV Vulnerability among Two-Spirit Youth who Migrate to Toronto

Doris O’Brien Teengs¹ and Robb Travers²

ACKNOWLEDGEMENTS

The authors express their gratitude to members of the Youth Migration Project team including, Carol-Anne O’Brien, Humberto Carolo, Llewellyn Goddard, Florence Heung, Andrea Ridgley, Suhail Sameed, and Kyle Scanlon. This research was made possible through funding support from Health Canada (Community-Based HIV/AIDS Research Program) as well as Toronto-based, Wellesley Central Health Corporation. We’d also like to express our appreciation to all of the youth who shared their stories with us in order to help the next generations of two-spirit youth.

ABSTRACT

Like most large urban centres in Canada, Toronto is a magnet for two-spirit youth who leave reserve communities and smaller cities and towns seeking safety and a sense of community. The Youth Migration Project was a community-based research project that was formed out of increasing community concern for these youth as well as other lesbian, gay, bisexual, and transgender young people. Despite increasing HIV incidence among two-spirit youth, little is understood about how their migration experiences might heighten their risk for HIV infection. We interviewed thirteen two-spirit youth to better understand how migrating to a large urban centre like Toronto is linked to heightened HIV vulnerability. We also interviewed an additional eight key informants seeking their insights into the same questions. Two-spirit youth spoke of escaping abusive, oppressive and homophobic home communities, and their dreams of a better life in Toronto. Once they arrived in Toronto, however, the illusion of an accepting and welcoming community was shattered. Racism, poverty, unemployment, unstable housing, inaccessible services, and sexual exploitation were commonly experienced by two-spirit youth. Many coped with their new situations by engaging in survival sex to pay the bills, or by using substances to cope with isolation, loss, and emotional pain. These factors can lead to potentially heightened risk situations for HIV among migrant two-spirit youth. In addition to a series of recommendations intended to meet their immediate service needs, we propose numerous strategies for longer-term change to improve quality of life for migrant two-spirit youth.

INTRODUCTION

“Life is about change. You have to move like a river. It’s not the same water, it’s always different.”
(male, 25, gay)

Like most large urban centres in Canada, Toronto is a magnet for two-spirit youth who leave reserve communities and smaller cities and towns seeking safety and a sense of community. The Youth Migration Project (YMP) was a community-based research project that was formed out of increasing community concern for these youth as well as other lesbian, gay, bisexual, and transgender young people. Despite increasing HIV incidence among two-spirit youth, little is understood about how their migration experiences might heighten their risk for HIV infection.

¹ HIV/AIDS Outreach Worker, 2-Spirited People of the 1st Nations and Ontario Aboriginal HIV/AIDS Strategy, 43 Elm St. 2nd Floor, Toronto, ON M5G 1H1, 416 944 9300, doe@2spirits.com

² Scientist and Director of Community-Based Research, Ontario HIV Treatment Network, 1300 Yonge St. Suite 308, Toronto, ON M4T 1X3, 416 642 6486 ext. 311, rtravers@ohntn.on.ca

This article was born out of the voices of two-spirit³ youth. We found that there was a large enough sample of two-spirit youth experiences within YMP for us to make some observations and recommendations. Our hope is that these recommendations will lead to better service delivery for migrant two-spirit youth at risk of HIV infection. The partnership model utilized in the Youth Migration Project (community workers and academic researchers working in collaboration) is reflected in this article. In this article we look at the historical and social factors that impact on Aboriginal people and how two-spirit youth who migrate to Toronto become vulnerable to HIV infection.

ABORIGINAL PEOPLE AND HIV/AIDS

The face of the HIV epidemic in Canada is clearly changing; one extremely alarming trend is the considerable increase in new infections among Aboriginal⁴ peoples (Archibald, Sutherland, Geduld, Sutherland & Yan, 2003). Between 1996 and 1999, the total number of Aboriginal people in Canada with HIV increased by 91%, and, in 1999 alone, they accounted for almost 9% of new HIV infections (Health Canada, 2001). By 2002, Aboriginal people accounted for approximately 12% of the total of new HIV infections, yet they represented only 3% of Canada's population (Canada Communicable Disease Report, 2003). Prior to 1993, just over 1% of reported AIDS cases were among Aboriginal peoples; by 2003, this had increased to over 13% (HIV/AIDS Epi Notes – Aboriginal Peoples, 2004). Moreover, in 1998, 19% of people testing positive were Aboriginal and by 2003, this had increased to 25% (HIV/AIDS Epi Notes – Aboriginal Peoples, 2004).

Aboriginal peoples are also acquiring HIV at a younger age compared to other groups in Canada (HIV/AIDS Epi Notes – Aboriginal Peoples, 2004). Myers et al (1993), report that 70% of Aboriginal youth are sexually active by the time they are 15 years old but less than 20% are using condoms consistently. According to the Canadian Aboriginal AIDS Network (2004, p.3), “30% of Aboriginal HIV infections are among youth between 20-29 years old (compared to only 20% in the non-Aboriginal population), and research indicates that the potential for the virus to spread among youth is enormous.”

Compared to other young gay and bisexual men in Canada, those who are Aboriginal are more likely to be unemployed and impoverished, on social assistance, in unstable housing, and relying on sex trade work to survive (Heath et al, 1999). They are also at greater risk of sero-converting over time compared to non-Aboriginal youth (Weber, Chan et al, 2001; Weber, Craib, et al, 2001). One author contends that “many young two-spirit men who migrate to Vancouver are becoming infected with HIV within 2 years” (McLeod, 1997).

LGBT PEOPLE AND MIGRATION

In recent years, a new body of literature has begun to emerge on lesbian, gay, bisexual and transgender (LGBT) people and migration. This literature is allowing for reconceptualizations of sexual identity, geography and migration (Altman, 2001; Bell & Valentine, 1995; Ingram et al, 1997; Parker & Gagnon, 1995). Herdt (1997) argues that existing models of sexuality and the life course from Kinsey onward assume a stable geography. Espin (1997) elaborates on this theme in her discussion of immigrant Latina lesbians, observing that migration often occasions shifts in sexual and gender identity; which may be a particularly difficult process to negotiate for those migrating during adolescence.

Some scholars have elaborated a notion of “queer diasporas” and charted the internationalization of gay identities (Altman, 2001; Gopinath, 1996; Parker et al, 1992; Patton, 1994; Stychin, 2000). To explore the ways in which sexuality figures in the decision to migrate, some scholars consider how migration processes may be shaped by

³ In this article two-spirit means a gay, lesbian, bisexual and/or transgender Aboriginal person. The term two-spirit was coined by Aboriginal lesbian and gay people in the late 1980s to refer to Aboriginal (First Nations and Métis, but not including Inuit) people who traditionally held either a special gender or social status in their respective cultures. As an English word, it crosses the cultural boundaries of Aboriginal cultures (there were and are slight differences in cultural beliefs and practices in North America with regards to this issue [Deschamps, 1998]).

⁴ For the purposes of this article, Aboriginal is inclusive of First Nations, Métis and Inuit people.

the recent development of an international gay culture, and by the construction of “gay capitals” such as San Francisco, New York and Amsterdam (Altman, 2001; Parker, 1999; Weston, 1998). There is some evidence that countries such as Canada and Australia, both of which have relatively open immigration policies with respect to lesbians and gay men, may attract migration by LGBT people for that reason (Myers et al, 2001; Peter and Sullivan, 1998; Stychin, 2000). Parker (1999) and Weston (1998) explore how LGBT migration is linked to a “gay imaginary” of urban gay life. Parker’s work on men who have sex with men in Brazil (1999) locates this within the social, economic and political processes that shape migration patterns generally. Weston (1998), Patton (1994) and Espin (1997) also link sexual migration to social and economic contexts and point out that it has implications for individual sexual/gender identities as well as for community formation.

This international literature has resonance in Canada, where gay villages in large cities – particularly Toronto - have attracted migrants from across the country. Based on initial statistical modelling (but validated by data from the Omega Cohort Study of Seronegative Men in Montreal), 57% of Montreal’s gay male population were born outside of the province of Quebec. The proportion of migrants in Toronto’s LGBT communities would be higher given that it is an even larger migration centre than Montreal and given its relatively new status as one of the world’s major urban gay centres (Remis, personal communication, 2002).

ABORIGINAL PEOPLE & MIGRATION

Migration has been very significant in the history of Aboriginal people in Canada (Report of the Royal Commission on Aboriginal Peoples, 1996; Vernon, 2001). Contemporary Aboriginal communities in Canada continue to be highly mobile, with one study indicating that 25% of Aboriginal people in Toronto had recently migrated from other communities in the recent past (Ontario Aboriginal HIV/AIDS Strategy, 1996). These migrations take place for a variety of social and economic reasons (Proceedings of “Healing Our Nations”, 1996).

Two-spirit people and Aboriginal PHAs (including youth) encounter additional pressures to leave their communities. The literature suggests that homophobia and negative reactions to PHAs on reserves combined with a lack of health and social services lead Aboriginal people to move to urban areas (Ontario Aboriginal HIV/AIDS Strategy, 1996; McLeod, 1997). The Canadian Aboriginal AIDS Network (2004) maintains that while migrating to large urban centres puts Aboriginal youth at risk for HIV, it also serves as a means of coping with the hardships of racism, colonization, violence and poverty. Deschamps (1998) states: “As two-spirited men, you know there is no room for your life on the reserve. Your sexuality is not tolerated and many men leave to find urban centres where they can express themselves.” In a survey of 658 people in First Nations communities in Ontario, it was reported that “...the majority of respondents felt that homosexuality was wrong, and believed their family and community to support this view” (Myers et al, 1993).

Some researchers document the positive role of migration in identity formation for two-spirit people across North America (Ontario Aboriginal HIV/AIDS Strategy, 1996; Deschamps, 1998; Medicine, 1997; Weston, 1998). It has been argued that HIV vulnerability is not due to migration itself, but to broader social and economic inequalities that mark the lives of those who migrate (Haour-Knipe & Rector, 1996, Sabatier, 1996). Others are concerned that processes of migration, return and re-migration facilitate the transmission of HIV among Aboriginal people (Canadian Aboriginal AIDS Network, 1998). The impact of migration has also been identified as particularly serious for two-spirit youth who are often unable to find employment, who lack other resources and must turn to the sex trade for survival (Deschamps, 1998; McLeod, 1997).

THIS STUDY

A key challenge in HIV prevention is understanding the unique vulnerabilities of two-spirit youth in relation to HIV infection. Indeed, little is known about this vulnerable group of youth. Understanding increased infection rates in a marginalized population demands that we move beyond psychological explanations such as the myth that youth believe themselves to be invulnerable to HIV infection (see, for example, Hays, Kegeles & Coates,

1990; Yarber & Sanders, 1998) to situate HIV risk in a broader social context of poverty and other forms of inequality (Namaste, 1999; Trussler & Marchand, 1997). Increasingly, evidence suggests that broader social factors (e.g., race and ethnicity, housing, poverty, etc.) are associated with increased risk for HIV infection among gay youth (Greenland et al, 1996; Denning, Jones & Ward, 1997; Travers & Paoletti, 1999). Moreover, little is understood about the role of migration to large urban centres like Toronto in understanding HIV vulnerability among two-spirit youth. It is this gap that this study intends to fill.

METHOD

Data were drawn from the Youth Migration Project, a community-based research (CBR) project comprised of seven community and two university-based investigators who came together to better understand HIV vulnerability among lesbian, gay, bisexual, transgender and two-spirit youth who migrate to Toronto from other parts of the world, and from smaller cities and towns, rural areas and reserve communities in Canada. Included in the team investigators is the principal author, Doris O'Brien Teengs, who is of mixed heritage of Cree and Irish Canadian descent and is a member of the Weenusk First Nation. Doris currently works at Toronto-based 2-Spirited People of the 1st Nations and the Ontario Aboriginal HIV/AIDS Strategy as an HIV/AIDS Outreach Worker. She joined the Youth Migration Project during the project formulation phase. The co-author, Robb Travers currently works at the Toronto-based Ontario HIV Treatment Network as Director of Community-Based Research. Robb was one of the initiators of YMP and served as Co-Principal Investigator for the life of the study.

Confidential and in-depth individual interviews and focus groups were held with 82 youth and 18 key informants. In the initial phase of YMP the team consulted key informants (Aboriginal and Métis workers and youth) to determine research priorities and questions specific to two-spirit youth. The YMP team then developed the questions and parameters for the interviews and the focus groups, which was then fine-tuned by the Principal Investigators.

Informed consent was obtained prior to participating in an interview or focus group. Study objectives were fully explained to participants, consent forms were administered by the interviewer or the focus group facilitator, and study participants received a stipend of \$20.00 for their participation. Following the interviews, youth were provided with counselling supports and resources if necessary. Interviews were taped and transcribed and the data were managed using FOLIO Views 4.2 Electronic Publishing Software. The Youth Migration Project received ethics review approval from the Research Ethics Board of Ryerson University in Toronto.

This paper draws on the data from thirteen two-spirit youth, 90% of whom had migrated to Toronto within the previous five years, and who ranged in age from 18 to 25. Data from an additional eight key informants (including Aboriginal youth workers, HIV/AIDS workers, and policy experts), are also included.

Numerous principles of CBR guided the work of YMP. Of particular significance, was our desire to ensure that community team members felt ownership of the research and its outcomes. To accomplish this, community-based investigators led discussions about the 'meanings' emerging from the data. In keeping with the CBR principle of capacity-building (Narciso, Travers, Mumford & Edwards, 2002), it was important for the Principal Investigators to demystify research processes; thus, we conducted a series of participatory data analysis sessions where all team members were involved in a thorough reading of select transcripts (i.e., those most relevant to their communities and in this case, any data from two-spirit youth included Doris O'Brien Teengs). In these sessions, we worked collaboratively to interpret data, to identify themes, and to make recommendations for change.

In order to give priority to the voices and lived experience of two-spirit youth, their quotes are largely used in the following section.

FINDINGS

“Turbulent Waters” – Why Two-Spirit Youth Migrate to Toronto

Two-spirit youth recounted many reasons for leaving their home communities, including experiencing oppression, violence and anti-gay discrimination. As one young man succinctly stated “the streets are safer than home” and as one key informant stated “homophobia drives youth away from reserves and other communities.” When faced with this unrelenting storm on a daily basis, youth leave because it is an alternative to suicide – an escape from hopeless situations.

“I was tormented all the way until I was in the ninth grade.” (trans mtf – male to female – youth, 22)

“I moved here because the reserve that I’m from... they’re totally against gay or bisexual people. I lived pretty much my whole life trying to pretend to be straight. I had enough of it.” (male, 19, bisexual)

Parents and siblings were often homophobic, mirroring attitudes present in the broader community.

“I had the worst time coming out of the closet in my reserve. They gay-bashed and everything. My family dropped me... my cousins, my friends... basically I was driven off of the reserve.” (male, 25, gay)

“Looking for Fair Weather” – Why Two-Spirit Youth Migrate to Toronto

Another significant reason for leaving their home communities lay in the desire to find a supportive and safe place to live out their lives. The anonymity offered by a large urban centre like Toronto made the big city highly desirable.

“I want to be able to land an apartment and go to work and lead a normal life like everybody else... and know that I have a warm home to come home to.” (male, 25, gay)

The decision to move to Toronto was most often made in haste. There was little time to plan and youth often left with little money in their pockets. Consequently, they were usually ill-prepared for life in the big city.

“Someone bought me the ticket and then I just came here with a purse. I got on a bus for Toronto.”
(trans mtf, 16)

“Paddling Upstream”: Life in Toronto

There were many challenges facing youth when they arrived in Toronto. Their dream of a safe place to live out their lives was quickly replaced by the reality of a large and expensive city where racism, exploitation and loneliness were commonly experienced. Most were ill-prepared for this and were shocked by landlords who refused to rent apartments, employers who refused to hire them, and the brutality of quickly becoming homeless.

“I had hell when I first moved here. I thought it was going to be easy. It wasn’t. It was really hard.”
(male, 23, gay)

While a very small minority found employment and housing, life quickly became a game of survival for the majority. Some stayed with friends for short periods of time, moving around from one place to another, while others relied on sexual partners they met to provide temporary shelter.

“I never stayed in shelters... If I went out, I picked up and I went home with that guy. Or, I went to the bathhouse.” (male, 24, gay)

“I came with somebody and they used prostitution to get by. I didn’t. I just used resources...the food banks... anywhere to go... just at least to get a bite to eat.” (male, 19, gay)

Given the instability of these temporary housing situations, many ended up on the street for periods of time.

“There was this one point in time where I was living under a bridge.” (trans mtf youth, 16)

“Someone’s Else’s Big Waters” – We’re not Welcome Here....

Youth and key informants frequently spoke of the racism toward two-spirit youth that was commonplace in the mainstream gay community. They spoke of the search for community, of the struggle to be accepted, and of trying to fit in.

“I found a community that was extremely unhealthy. I went into a gay community that revolved around alcohol or drugs. ...You’re looking at acceptance. You’re finding out about the hierarchy of the community. And if you don’t fit in within those particular specifics, then you’re fucked even more. ...If you’re not wearing Calvin Klein underwear then you’re fucked. So you open yourself up to even more criticisms, and more at-risk behaviours.” (male, 24, gay)

Many youth found a social gay community that they could participate in which revolved around the party scene; consequently, many of the two-spirit youth in this study developed problems with alcohol and drugs and many recounted their own struggles or those of their friends.

“Probably just the alcoholism. Somebody is so blasted and someone takes them home and corrupts their little life. They don’t realize that it feels good for the moment but what about the after-effects?” (male, 25, gay)

“A Dam in the River...”

Two-spirit youth in this study also encountered barriers when they sought out services. Attitudes toward two-spirit people tended to emulate those of their home communities and they were further marginalized by Aboriginal people. Incidents of homophobic discrimination in mainstream Aboriginal agencies were common and this furthered their sense of alienation and isolation from the larger Aboriginal community.

“I prefer to come here (two-spirit program) because it’s safer. You know what I mean? I don’t get called a ‘faggot’ and I don’t get stared down at when I’m walking down the street because I’m not trying to hide who I am.” (male, 25, gay).

Rarely were they referred to an agency where they could receive services such as those offered by 2-Spirited People of the 1st Nations.

“I didn’t know about this place until six months later. Nobody talked about it. I never used to see it. I went to all the Native agencies in Toronto and I never saw anything about two-spirits... no postings, nothing.” (male, 25, gay)

“Murky Waters” – Sexual Exploitation

Some of the youth in this study had been exploited sexually by older white males after arriving in the city. Their alienation and isolation left them lonely and vulnerable to sexual exploitation.

“This guy brought me there. He was asking for sex. I looked around and everywhere I looked there were cockroaches. He told me that he wasn’t a pedophile... that he was a really nice guy and that he would like to help me.” (trans mtf, 16)

Another youth recounted how he would have unprotected sex when he was drunk.

“It usually happens when I’m drunk. When I’m in a different state of mind because you’re a whole different person when you’re drunk.” (male, 25, gay)

These examples illustrate the loneliness of two-spirit youth and their vulnerability which can lead to unhealthy coping mechanisms. Most of the youth in the study were unhappy with their new lives and felt uncertain about their futures. In fact, most of the youth did not choose to think about the future beyond one or two days.

“I can’t remember the last time I was happy and carefree and I didn’t have to worry. The day will come eventually, hopefully.” (male, 19, bisexual)

“It’s in the water” – What’s the HIV connection?

Aboriginal communities experience a wide range of challenges including poverty, violence, suicide and hopelessness. The legacy of residential schools has also left many with negative assumptions about same-sex attraction. The widespread sexual abuse that occurred makes it difficult for many to have a healthy view of sexuality. Instead, sexuality has become a source of shame and pain. Complicating matters is that community members might even perceive people with same-sex attractions to be potential perpetrators.

The migration experiences of two-spirit youth are precipitated by a desire to find a safe and welcoming place to live out their lives. Unlike youth raised in cities, two-spirit youth have no access to visible role models in their home communities, they have few places to hide if they are discovered or suspected, and they experience considerable and persistent harassment. For those youth in very small communities, this may mean that everyone in town knows of their sexual orientation or gender identity.

Homophobia in their families and in their broader home communities leaves them little choice but to migrate to the city. This can lead to a crisis, and services for two-spirit youth are rare outside of large urban centres. Some of these youth migrate to Toronto, arriving without a plan or direction, and as a result of quitting school early and possessing few job skills, they are ill-equipped to deal with the pace of urban life and its realities.

Thus, two-spirit youth start out searching for a safe place to explore and live out their gay, bisexual, or trans identities and instead encounter inequality and discrimination at almost every turn. Many end up feeling as if they don’t matter and that their lives are unimportant. The end result is isolation from their home communities, from the urban Aboriginal communities and a profound loss of cultural identity.

Because they do not need a resume, many two-spirit youth turn to the sex trade to survive, while others find themselves in a gay social scene which revolves around drug and alcohol use. Some of them are sexually exploited either because they are intoxicated or simply because they are emotionally vulnerable. Irrespective of the particular outcome, these are all situations where the risk for HIV infection is heightened. When two-spirit youth are in a situation where survival depends on other people’s generosity, or where harmful amounts of alcohol or drugs are used as coping strategies, these youth become vulnerable to HIV. Moreover, when housing, food, money and personal safety are more immediate and urgent concerns, the ability or desire to protect

oneself in risk situations lessens. Taken in combination, these factors must be attended to in order to lessen HIV vulnerability among two-spirit youth.

“Building New Bridges” – Recommendations:

Improving conditions for migrant two-spirit youth will involve addressing the broad social determinants of health that heighten their risk for HIV including housing, poverty, and social exclusion (in this case, homophobia in their home communities which precipitates migration, further marginalization in urban Aboriginal agencies, and the racism they encounter in gay communities in Toronto). 2-Spirited People of the 1st Nations has embarked upon an initiative to eliminate homophobia in Aboriginal communities. They have developed a ‘Two-spirits 101’ curriculum to offer organizations. One version includes anti-racism training for lesbian, gay, bisexual and transgender services, while another is designed for mainstream Aboriginal agencies or other services offering programming to Aboriginal clients.

Youth do not often arrive in Toronto with a high school diploma. In order to enhance literacy skills among two-spirit youth, targeted culturally-relevant and sensitive initiatives in urban centres such as Toronto are urgently needed.

While attending to these more systemic issues will take time and concerted advocacy efforts, immediate steps can be taken to enhance the ability of migrant two-spirit youth to survive in large urban centres like Toronto. More immediate solutions include the development of resources for service providers that provide practical advice on working with two-spirit youth including a list of local resources to meet their needs. Similar resources should be developed for youth that advise them of local counselling services, HIV programs, available housing options, and food banks.

Two-spirit youth also require programs and resources designed to restore their cultural identities. These resources can be web-based or in print form but should attend to rebuilding a positive sense of two-spirit culture and identity. These programs would also have to take into consideration the high percentage of Aboriginal youth that have been adopted and fostered into non-Aboriginal families who are searching for their roots and have a tenuous connection to Aboriginal people.

Two-spirit youth also require support and social venues that are youth-friendly and specific. Currently, many two-spirit youth socialize and receive support services alongside adults (again increasing their risk of adult exploitation). Youth-specific support services should be designed in a manner to facilitate learning about two-spirit issues, positive Aboriginal identity, and traditional cultural teachings. Other components would include communicating with family, harm reduction counselling for substance use and sessions dedicated to learning about HIV. Strategies that enhance outreach services are urgent for street-involved two-spirit youth. These should be inclusive of peer-based components designed to reach youth and hook them up to available services.

Finally, two-spirit youth require prevention programming tailored to their specific needs and concerns. The Canadian Aboriginal AIDS Network (2004, p.5) noted a tendency in HIV prevention materials targeted at Aboriginal peoples to treat them all as if they were a “homogeneous group.” Two-spirit youth, in particular, have unique HIV prevention needs and further research is required to determine the scope of these needs and the most culturally-appropriate means of delivering them.

RESEARCH LIMITATIONS

There are also some study limitations that should be taken into consideration when reviewing our data, our interpretations, and our recommendations. The Youth Migration Project limited its focus to youth who moved to Toronto. As such, it may be challenging to apply our findings across the board in other urban settings. We would suggest that you take what appears potentially useful and applicable and augment it by considering the particularities of your own urban setting.

Another limitation of our research is that we relied on snowball sampling methods to reach youth: initially, youth were contacted via flyers posted in youth-serving agencies and email listservs and we relied on their contacts to reach other youth. This was a purposeful strategy in that it was very difficult (due to mistrust of researchers) to reach even this small sample of two-spirit youth. Our final sample was well-connected to services and as a result, the 'stories of resilience and survival' that are surely out there, did not get included in our study. Despite these limitations, however, there were clear themes and consistencies in the youths' stories. This suggests to us that migrating to a large urban centre like Toronto has a clear and predictable set of outcomes that put two-spirit youth at considerable risk for HIV infection.

IMPLICATIONS FOR FURTHER RESEARCH

There is a need for further research to untangle the complexities of HIV vulnerability among migrant two-spirit youth as they negotiate life in urban settings. The pathway to HIV infection among two-spirit youth is long and complex and commands the development of culturally-appropriate methods that allow for longer-term engagement with youth. Immediate efforts should be focussed on culturally-appropriate HIV prevention programming for these youth, including the development of peer-based components.

CONCLUSION

Two-spirit youth who migrate to Toronto encountered a multitude of unique life experiences that challenge the stability of their housing, the ability to make an adequate income, the expectations of food security, and safety. Youth were subjected to exploitation and may rely on sex trade to survive. While getting 'sucked' into the scene, alcohol and drug use may be adopted as coping strategies leading to further complications brought on by the development of chaotic substance use. The combination of these factors renders them vulnerable to HIV infection. Ameliorating these risks for migrant two-spirit youth will require longer-term strategies, concerted advocacy efforts, and immediate program development. In combination, these strategies will ultimately improve quality of life for migrant two-spirit youth and reduce HIV incidence.

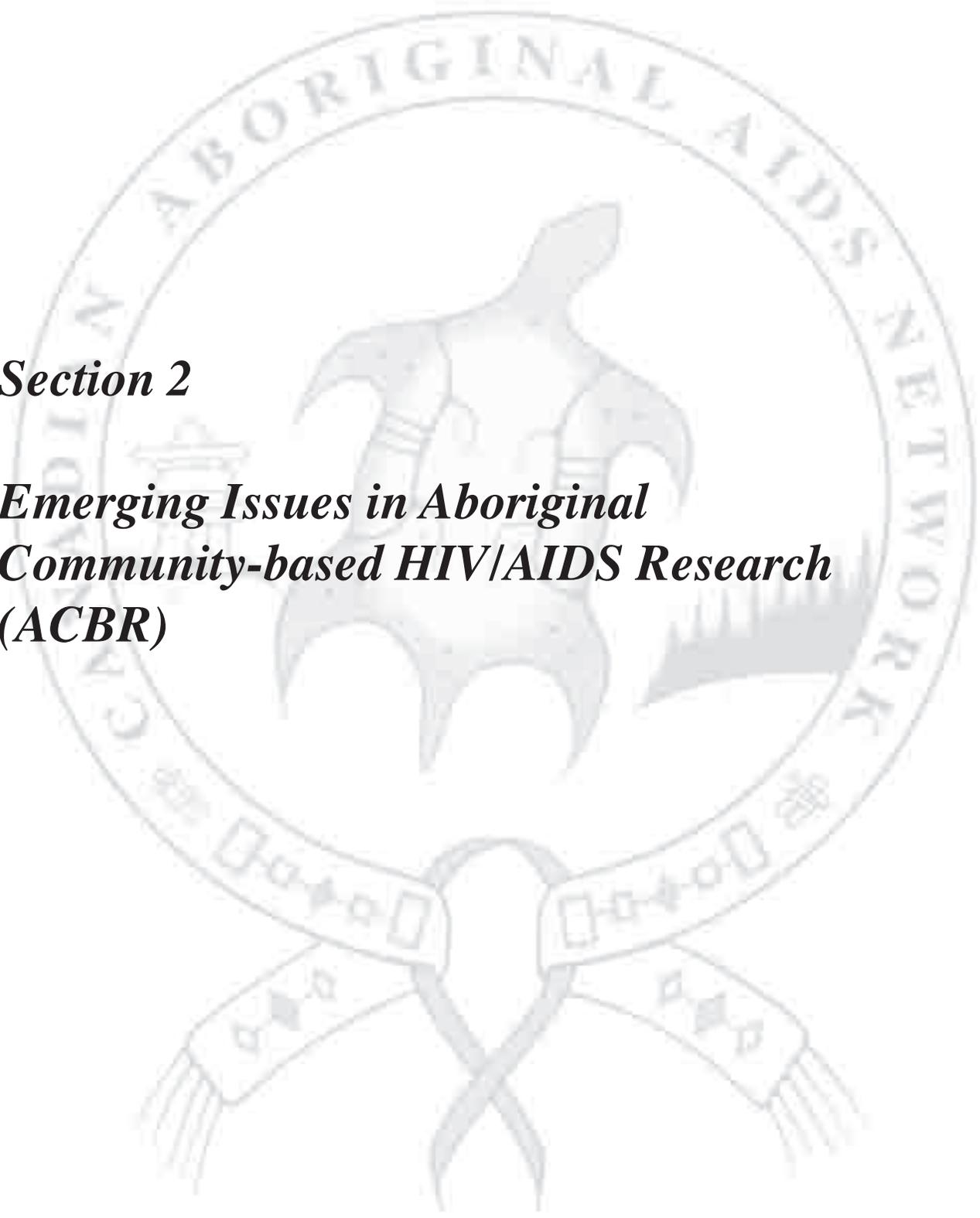
REFERENCES

- Altman, D. (2001). *Global Sex*. Chicago: University of Chicago Press.
- Archibald, CP., Sutherland, J., Geduld, J., Sutherland, D., & Yan, P. (2003). Combining data sources to monitor the HIV epidemic in Canada. *Journal of Acquired Immune Deficiency Syndromes*, 32 (Suppl 1), S24-32.
- Bell, D. & Valentine, G., eds. (1995). *Mapping Desire: Geographies of Sexualities*. London and New York: Routledge.
- Canada Communicable Disease Report (2003). Ottawa: Health Canada, Population and Public Health Branch. December, 2003, Vol. 29.
- Canadian Aboriginal AIDS Network. (1998). *Learning from Our Past, Planning for Our Future: HIV/AIDS Aboriginal Skills Building Forum*. Ottawa: CAAN.
- Canadian Aboriginal AIDS Network. (2004). *HIV Prevention: Messages for Aboriginal Youth*. Ottawa: CAAN.
- Denning, P.H., Jones, J.L., & Ward, J.W. (1997). Recent trends in the HIV epidemic in adolescent and young adult gay and bisexual men. *Journal of Acquired Immune Deficiency Syndromes & Human Retrovirology*, 16, 374-379.

- Deschamps, G. (1998). *We Are Part of a Tradition: A Guide on Two-Spirited People for First Nations Communities*. Toronto: 2-Spirited People of the 1st Nations.
- Espin, O. (1997). Crossing borders and boundaries: The life narratives of immigrant lesbians. In Beverley Greene, ed., *Ethnic and Cultural Diversity Among Lesbians and Gay Men*. Thousand Oaks: Sage.
- Gopinath, G. (1996). Funny boys and girls: Notes on a queer South Asian planet. In Russell Leong, ed., *Asian American Sexualities: Dimensions of the Gay and Lesbian Experience*. New York: Routledge.
- Greenland, S., Lieb, L., Simon, P., Ford, W., & Kerndt, P. (1996). Evidence for recent growth of the HIV epidemic among African-American men and younger male cohorts in Los Angeles County. *Journal of Acquired Immune Deficiency Syndromes & Human Retrovirology*, 11, 401-409.
- Haour-Knipe, M., & Richard, R. eds. (1996.) *Crossing Borders: Migration, Ethnicity and AIDS*. London: Taylor and Francis.
- Hays, R.B., Kegeles, S.M., & Coates, T.J. (1990). High HIV risk-taking among young gay men. *AIDS*, 4, 901-907.
- Heath, K.V., Cornelisse, P.G.A., Strathdee, S.A., Palepu, A., Miller, M.L., Schechter, M.T., O'Shaughnessy, M.V., & Hogg, R.S. (1999). HIV-associated risk factors among young Canadian Aboriginal and non-Aboriginal men who have sex with men. *International Journal of STD & AIDS*, 10, 582-587.
- Health Canada (2001). *HIV/AIDS Epi Update May, 2001 (National HIV prevalence and incidence estimates for 1999: No evidence of a decline in overall incidence)*. Ottawa: Bureau of HIV/AIDS, STD and TB Update Series. Centre for Infectious Disease Prevention and Control.
- Herd, G. ed. (1997) *Sexual Cultures and Migration in the Era of AIDS: Anthropological and Demographical perspectives*. Oxford: Clarendon Press.
- HIV/AIDS Epi Notes – Aboriginal Peoples. (2004). *Understanding the HIV/AIDS Epidemic among Aboriginal Peoples in Canada: The Community at a Glance*. Ottawa: Public Health Agency of Canada.
- Ingram, G., Bouthillette, B. & Retter, Y. (1997). *Queers in Space: Communities/Public Places/Sites of Resistance*. Seattle: Bay Press.
- McLeod, A. (1997). *Aboriginal Communities and HIV/AIDS: A Joint Project with the Canadian AIDS Society and the Canadian Aboriginal AIDS Network. Final Report*. Ottawa: Canadian AIDS Society.
- Medicine, B. (1997). Changing Native American roles in an urban context and changing Native American sex roles in an urban context. In Sue-Ellen Jacobs et al, eds., *Two Spirit People*. Urbana and Chicago: University of Illinois Press.
- Myers, T., Calzavara, L., Cockerill, R., Marshall, V.W., Bullock, S.L., & the First Nations Steering Committee. (1993). *Ontario First Nations AIDS and Health Lifestyle Survey*. Ottawa: National AIDS Clearinghouse, Canadian Public Health Association.
- Myers., T., Travers, R., Allman, D., Lau, W., Maxwell, J., & Calzavara, L. (2001). *An HIV_Research Needs Assessment of MSM in Ethno-Cultural Communities: Perspectives of Volunteers and Service Providers*. Toronto: HIV Social, Behavioural and Epidemiological Studies Unit, University of Toronto.

- Namaste, V. K. (1999). HIV/AIDS and female-to-male transsexuals and transvestites: Results for a needs assessment in Quebec. *The International Journal of Transgenderism. Special Issue on Transgender and HIV: Risks: Prevention and Care* 3 (1 and 2).
- Narciso, L., Travers, R., Mumford, B., & Edwards, S. (2001). *Community-Based Research: An Approach to Building Sustainable Capacities in the HIV/AIDS Community*. Poster presented at the 1st International Conference on Inner City Health. Toronto.
- Ontario Aboriginal HIV/AIDS Strategy. (1996). *Ontario Aboriginal HIV/AIDS Strategy*. Toronto. Parker, R. G. & Gagnon, J. H., eds. (1995). *Conceiving Sexuality: Approaches to Sex Research in a Postmodern World*. New York and London: Routledge.
- Parker, A., Russo, M., Sommer, D. & Yeager, P. (1992). *Nationalisms and Sexualities*. New York and London: Routledge.
- Parker, R. (1999). *Beneath the Equator: Cultures of Desire, Male Homosexuality, and Emerging Gay Communities in Brazil*. New York: Routledge.
- Patton, C. (1994). *Last Served? Gendering the HIV Pandemic*. London: Taylor and Francis.
- Peter, J. L. & G. Sullivan, eds. (1998). *Multicultural Queer: Australian Narratives*. New York: Haworth Press.
- Proceedings of "Healing Our Nations" (1996). 4th Canadian Aboriginal Conference on HIV/AIDS and Related Issues. Halifax.
- Remis, R.S. (2002). Unpublished statistical modeling migration data. Department of Public Health Sciences, University of Toronto.
- Report of the Royal Commission on Aboriginal Peoples. (1996). Ottawa: Ministry of Supply and Services.
- Sabatier, R. (1996). Migrants and AIDS: Themes of vulnerability and resistance. In M. Haour-Knipe and R. Rector, eds., *Crossing Borders: Migration, Ethnicity and AIDS*. London: Taylor and Francis.
- Stychin, C. (2000). 'A stranger to its laws'. Sovereign bodies, global sexualities, and transnational citizens. *Journal of Law and Society*, 27, 601-625.
- Travers, R., & Paoletti, D. (1999). Responding to the support needs of HIV positive lesbian, gay and bisexual youth. *Canadian Journal of Human Sexuality*, 8 (4), 271-283.
- Trussler, T. and Marchand, R. (1997). *Field Guide. Community-Based HIV Health Promotion*. Ottawa: Health Canada/AIDS Vancouver.
- Vernon, I.S. (2001). *Native Americans and HIV/AIDS*. Lincoln: University of Nebraska Press.
- Weber, A.E., Chan, K., George, C., Hogg, R.S., Remis, R.S., Martindale, S., Otis, J., Miller, L., Vincelette, J., Craib, K.J.P., Mâsse, B., Schechter, M.T., Leclerc, R., Lavoie, R., Turmel, B., Parent, R., & Alary, M. (2001). Risk factors associated with HIV infection among young gay and bisexual men in Canada. *Journal of Acquired Immune Deficiency Syndromes*, 28, 81-88.
- Weber, A.E., Craib, K.J.P., Chan, K., Martindale, S., Miller, M.L., Schechter, M., & Hogg, R.S. (2001). Sex trade involvement and rates of human immunodeficiency virus positivity among young gay and bisexual men. *International Journal of Epidemiology*, 30, 1449-1454.

- Weston, K. (1998). Get thee to a big city: Sexual imaginary and the great gay migration. In K. Weston. *Longslowburn: Sexuality and Social Science*. New York: Routledge.
- Yarber, W. L., & Sanders, S. A. (1998). Rural adolescent views of HIV prevention: Focus groups at two Indiana rural 4-H clubs. *The Education Health Monograph 16* (2), 1-6.



Section 2

*Emerging Issues in Aboriginal
Community-based HIV/AIDS Research
(ACBR)*

Knowledge Translation and Aboriginal HIV/AIDS Research: Methods at the Margins

Renee Masching¹, Yvon Allard² and Tracey Prentice³

ACKNOWLEDGEMENTS

The authors would like to acknowledge Judy Mill (Principle Investigator) and the research team of the “Diagnosis and Care of HIV Infection in Aboriginal Youth” research project for allowing us to reference this project before the final report has been published. In addition, we would like to honour the excellent work that is being done at the community level by the other organizations named in this article and the many other outstanding organizations who are united in a response to HIV/AIDS in Aboriginal communities from sea to sea to sea.

ABSTRACT

Research can provide useful evidence to better target health policy, and to guide more effective health services and programs. Aboriginal health research is a critical part of the complex social and political processes that maintain health services and programs and in the broader determinants of health. No longer is Aboriginal research being done *to* Aboriginal peoples, instead research is conducted *with* and *by* Aboriginal peoples, organizations and communities. It is imperative that HIV/AIDS is acknowledged as a health priority across all health services and that effective partnerships for community action are developed with Aboriginal communities. Community members need to be meaningfully involved in designing, promoting and implementing HIV/AIDS prevention and treatment programs.

This article explores the process of knowledge translation (KT) in Aboriginal HIV/AIDS research as a tool of community-based research and a process that is consistent with the principles of ownership, control, access, and possession (OCAP) in Aboriginal research. Examples of KT initiatives are drawn from the Aboriginal HIV/AIDS movement in Canada. KT processes ensure Aboriginal community involvement in all aspects of the research process including: Aboriginal direction and guidance in setting the research question(s), doing the research, writing, reviewing and reading the final academic and community publications (Allard 2006). Effective KT requires significant planning in advance, working in-person with the support of Elders, ongoing learning and direct community involvement throughout the project which leads to deeper investment in the results and greater capacity to take action (Masching et al. 2006).

INTRODUCTION

Knowledge Translation (KT) is a concept that captures the strong desire for research results to be ‘taken up’ and applied in practical ways that will lead to action (Estabrooks, Thompson, Lovely & Hofmeyer, 2006; Graham et al., 2006, Lavis, 2006). This is a somewhat new concept and new terminology in research that began to gain in popularity in 2000 (Canadian Institutes of Health Research (CIHR), 2004; Stirling & Bisby, 2006). Building on the notions of knowledge transfer and dissemination, KT moves towards a more interactive and reciprocal research process involving both academic and community researchers (Canadian Institutes of Health Research (CIHR), 2006a, 2006b). For Aboriginal Peoples in Canada the principles of KT (Martin, MacAulay, McComber, Moore & Wein, 2005; Reading, 2005; Smylie, et al., 2003) complement and support the expectations outlined in the philosophies of Aboriginal ownership, control, access and possession (OCAP) (Schnarch, 2004), and

¹ Research Technical Assistant, Canadian Aboriginal AIDS Network (CAAN), Ottawa ON, 902.405.6343, reneem@caan.ca

² Research and Policy Officer, Métis Centre at National Aboriginal Health Organization (NAHO), Ottawa ON, 613.237.9462 ext 596, yallard@naho.ca

³ Research Coordinator, McMaster University, Hamilton and Canadian Aboriginal AIDS Network (CAAN), Ottawa ON, 613.567.1817 ext 108, traceyp@caan.ca

implemented in community-based research (CBR) methodology (Canadian Aboriginal AIDS Network (CAAN), 2002a; Ibanez-Carrasco, 2004; Smith, 1999). This complimentary relationship further enhances the expectation that research will be meaningful and lead to positive change for Aboriginal Peoples in Canada.

KT emerged from the health sector (Bowen & Martens, 2005; Choi, 2005) and while there are many applications, the goal of this paper is to focus on KT as it relates to Aboriginal community-based health research and specifically to HIV/AIDS (Indyk & Rier, 2005; Majumdar, Chambers & Roberts, 2004; Willms, Arratia & Makondesa, 2004). A short review of the history of research *on* Aboriginal Peoples will lead into the evolution of the concept of Knowledge Translation and the philosophy of OCAP. Examples of the implementation of KT in Aboriginal community-based HIV/AIDS research (CAAN, 2005a, 2005b; Fletcher, 2003) are discussed within some of the opportunities that exist in Canada. Finally, the paper will reflect on the process of the integration of KT through to actions with suggestions for further research, evaluation and ideas to continue to apply KT from the grassroots to the National level.

BACKGROUND

There is a legacy of distrust, harm and exploitation caused by researchers that must be recognized when undertaking research with Aboriginal Peoples in Canada (Smith, 1999; Smylie et al., 2003; Stephens, Porter, Nettleton & Willis, 2006). Significant shifts have taken place in recent history and increasingly Aboriginal communities are poised to take a leading role in research. This shift is captured in the notion of doing research “with” Aboriginal Peoples rather than “on” Aboriginal Peoples. Respect and awareness of the past helps to guide us in the present and into the future towards a vision of strong healthy communities. As Aboriginal people engaged in research and a non-Aboriginal person coordinating an Aboriginal research project, the authors of this paper value KT. It is our perspective that KT reinforces the relevance of research for Aboriginal communities, improves the results of research and engages more people in the research process creating opportunities for mutual learning and capacity building.

Attention to the legacy of research is necessary for all researchers, Aboriginal or not, who hope to pursue health research within Aboriginal communities. Smylie et al. (2003) point out the importance of a new research relationship:

Conducting health research with Aboriginal peoples entails tremendous responsibility. Researchers have a responsibility not to perpetuate existing inequalities, policies and attitudes. Information should be collected in a way that is consistent with Aboriginal worldviews, respects cultural differences, protects their traditions and cultural manifestations and also recognizes the moral, historic and legal rights of Aboriginal peoples to self-determination. (p. 34)

When research is respectful of the perceptions, needs, unique circumstances and traditional knowledge in Aboriginal communities (Smith, 1999) the outcomes have been demonstrated to be extraordinary. The Kahnawake Schools Diabetes Prevention Program (Potvin, Cargo, McComber, Delormier & MacAulay, 2003) is a stellar example of a successful Aboriginal community-based research initiative that is conducted in line with the respectful relationship described by Smylie et al. (2003) above.

WHAT IS KT?

In 2000 new legislation was introduced in Canada to establish the Canadian Institutes of Health Research (CIHR) with, “a bold, transformative mandate that included both health research *and* knowledge translation” (CIHR, 2004). The CIHR consolidated several research funding bodies in one organization. The Institute of Aboriginal People’s Health (IAPH) is one of 13 institutes and was created in response to the unique health research needs of the Aboriginal population in Canada. The creation of the IAPH is important for Aboriginal research as noted by Stephens, et al. (2006) “this recommendation [for equal partnership] stems from the legacy of past research, and in some Indigenous communities a model of this participatory nature already exists. Canada’s First Nations

peoples, for example, have pioneered an Indigenous-led research agenda (p. 2025). Some of the work the IAPH-CIHR has funded includes Aboriginal KT projects, which are included in two casebook reports by the CIHR (CIHR 2006a, 2006b; Stirling & Bisby, 2006).

There is an expectation that CIHR funded research will lead to change, specifically to the improved health of the Canadian population. Knowledge Translation, “a prominent and innovative feature of the CIHR mandate” (CIHR, 2004), is defined as:

The exchange, synthesis and ethically-sound application of knowledge - within a complex system of interactions among researchers and users - to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system (CIHR, 2004).

Based upon this definition the expectation of all research is for “an active exchange of information between the researchers who create new knowledge and those who use it” (CIHR, 2004). Essentially, KT is about making sure that the knowledge gained through research is meaningful and useful in practice for various stakeholders. This means that from the very beginning of a research project plans and resources are in place for capacity building and information sharing throughout the project.

KT as a concept has been broadly taken up and distinguishes itself from ‘knowledge dissemination’ or ‘knowledge transfer’ with a focus on innovative and dedicated action and the quality of research prior to dissemination and implementation of research findings (National Centre for the Dissemination of Disability Research (NCDDR), 2005; Schryer-Roy, 2005). KT is a complex process that ideally results in behaviour change and positive health outcomes on the part of knowledgeable strategic planners and change agents, such as policy makers, community leaders, and governments (National Centre for the Dissemination of Disability Research, 2005). However, as noted by Ho et al. (2004) in relation to KT in medical settings, change is a long term goal: “It took some 264 years for evidence that vitamin C cured and prevented scurvy to inspire the British Navy to establish a routine dietary policy in its fleet. The current KT cycle, although much shorter, is still estimated to be more than 20 years” (ibid, p. 2).

OWNERSHIP, CONTROL, ACCESS AND POSSESSION

The philosophy of OCAP is a statement of principles for conducting research with Aboriginal communities. First put forward by the First Nations during the early phases of the First Nations and Inuit Regional Longitudinal Health Survey process OCAP has become a concise reference to the expectation that Aboriginal Peoples will be active and equal partners in the research process. In essence, ownership identifies the collective ownership of knowledge and information by Aboriginal Peoples. Control speaks to the right to control all aspects of the research process from conception to completion. This does not imply the right to exclusively conduct research, it is the right to be involved, to contribute, to approve and be aware of all aspects and impacts of the research as a project progresses. Access is two fold and reflects the right to have access to information about the community and also to manage and decide who else will have access to this data. Finally, possession is more literal and means to assert ownership and maintain the right to store all materials related to a research process (CAAN, 2002a).

The implementation of OCAP occurs in numerous ways. Various organizations and institutions have developed templates for team agreements that can be adapted as desired by a research team as new projects are initiated. The Canadian Aboriginal AIDS Network (CAAN) uses the Principles of Research Collaboration agreement in all research projects (Canadian Aboriginal AIDS Network, 2002b). This agreement clearly outlines expectations for all of the research project stakeholders and operationalizes how the principles of OCAP are implemented in community-based HIV/AIDS projects undertaken by CAAN. OCAP principles are also incorporated in ethical reviews by groups such as the Manitoulin Island Aboriginal Health Research Review Committee and the Mi’kmaq Ethics Watch (Noojmwowin Teg Health Centre, 2003; Mi’kmaq College Institute, 1999).

A significant outcome of the mobilization of research in the Aboriginal community around OCAP has been increased attention to capacity building (Fletcher, 2003; Smith, 1999). Naturally to exert rights grounded in self-determination and jurisdiction over community it is necessary to build relevant skills (CAAN, 2005a, 2005b, 2004, 2003). In light of this need,

The concepts of “participatory research” and “community involvement”, the incorporation of “traditional knowledge”, “culturally appropriate” and “community-based” research methods have gained momentum in recent years within First Nations and Inuit settings. (Schnarch, 2004, p. 6)

This momentum towards community driven research creates a distinct pathway to support the incorporation of KT (Fletcher, 2003), especially in HIV/AIDS research (CAAN, 2005a, 2005b, 2004; Ibanez-Carrasco, 2004). As Schnarch (2004) concludes “research is a tool for promoting changes that can transform people’s lives. Putting OCAP into practice enhances that potential” (ibid, p. 25). Similarly, KT seeks to put the results of research into practice in a meaningful way that will lead to action and change for the better (CIHR, 2006a, 2006b; Reading, 2005).

APPLYING KT PRINCIPLES IN ABORIGINAL RESEARCH

Given a growing understanding of KT in practice and in literature the opportunity is emerging to reflect upon the impact of this concept in Aboriginal research forums (Allard, 2006). For example, Smylie et al. (2003) noted that until recently, the “two communities” theory put forward by Caplan in 1979 has been the dominant model of health research in Aboriginal communities. This theory presents the notion that research uptake is limited by a divide between the “two communities” - one of health researchers and one of policy makers. The divide is due to differences in language, priorities and world view (Neilson, 2001). Commenting further on this theory, Smylie et al. (2003) observe:

In the century following the Indian Act legislation, “official” health researchers and policy makers were clearly external to Aboriginal communities, and largely employed by the Federal government. While health researchers remain external to Aboriginal communities today, health policy makers are increasingly found within the community, as the communities take a larger role in the governance and management of their health care services. This shift has resulted in a widening gap in the worldview between the two groups. Further research regarding knowledge translation in Aboriginal communities can narrow this gap in two ways: by applying a health research methodology that is framed in the indigenous worldview of the community “policy makers”; and by involving Aboriginal academics and community members in the health research process. (p. 141-142)

Likewise, NAHO produced a strategic paper that reviewed reports and articles published about Aboriginal Health between 1991 and 2001, in total, 250 references were identified (National Aboriginal Health Organization (NAHO), 2001). Clearly, research into Aboriginal health is occurring; the challenge is to ‘translate’ this body of knowledge into policy and practice. In the same document NAHO observes that when excluded from the research process, Aboriginal Peoples feel little ownership of the resulting knowledge. Given this lack of connection, policy decisions based on the evidence from the research are seen as lacking context, lose relevance and reinforce the history of *being* researched rather than acting together to improve community health (ibid). The end result of this exclusionary process is research that is not trusted and will not be taken up in policy that can fully contribute to improving health status and outcomes.

Finally, Kenny (2004) has presented an interesting Framework for Aboriginal Policy Research. Recognizing that sharing knowledge is a traditional norm, Kenny references, “sharing is a responsibility of research... For indigenous researchers sharing is about demystifying knowledge and information and speaking in plain terms to the community... Oral presentations conform to cultural protocols and expectations” (p. 13). Kenny emphasizes that research that is culturally relevant must honour “constant” communication with the community throughout the research process, “[a]fter all, lives will be affected by the changes the research may bring” (p. 13).

INCORPORATING KT IN AN ABORIGINAL COMMUNITY-BASED RESEARCH PROJECT

There is no one ‘formula’ for incorporating KT into an Aboriginal community-based research project. Instead, there are a variety of strategies that can be used that fall under the broad concept of Knowledge Translation (CIHR, 2004, 2006a, 2006b). The list includes:

Knowledge dissemination, communication, technology transfer, ethical context, knowledge management, knowledge utilization, two-way exchange between researchers and those who apply knowledge, implementation research, technology assessment, synthesis of results within a global context, development of consensus guidelines and more. (CIHR, 2004)

Furthermore there are distinctions in the audience the research is intended for and different types of research will require different approaches. The heart of the matter is that bringing users and creators of knowledge together during all stages of the research cycle is fundamental to successful KT (CIHR, 2004, 2006a, 2006b; Estabrooks et al., 2006; Graham et al., 2006; Grimshaw et al., 2006; Lavis, 2006; Reading, 2005; Schryer-Roy, 2005; Willms et al., 2004).

Through the development of a KT Toolkit for the Métis Centre at NAHO, Allard (2006) indicates that KT is grounded in both Knowledge Transfer and Knowledge Brokerage. Schryer-Roy (2005) also references these topics in her presentation, *Knowledge Translation: Basic Theories, Approaches and Applications*. In this context, Knowledge Transfer processes are pushed beyond the unidirectional dissemination of knowledge and incorporate “dynamic mechanisms for engaging stakeholders in order to increase their uptake and application of research information (and thereby enhance the decision making process)” (Allard, 2006). Knowledge Brokerage refers to “the human forces behind knowledge transfer... [and]... refers to the connections that ease knowledge transfer” (Schryer-Roy, 2005, p3).

In an effort to support research teams to plan for KT at the ‘front end’ of the research process, Allard (2006) has outlined 10 questions that will help to ensure that KT will be included in the research process. By answering these questions as the research proposal is being developed, the quality of the research plan will be increased and KT will be built into the process (refer to text box below). This is a useful process for each new project given the fact that answers to the KT questions are unique to each Aboriginal CBR project, as determined by the researcher and community committee discourse and decisions.

Q1. What is this project trying to achieve?

- What do you hope will happen as a result of the research project in regards to health status and outcomes in Métis/First Nation/Inuit communities?
- Is it likely to have an impact on health service provision, health professionals’ practice, policy and funding allocations, treatment options, building capacity, or informing healthy behaviour?

Q2. Who are the potential users of the outcomes or knowledge from the project?

- Evidence shows that the involvement of potential users in the planning, conduct and dissemination of projects is likely to assist the uptake of research.
- The research project committee has to ‘market’ (i.e. social marketing) the KT process to stakeholders, including the knowledge created by the research project.

Q3. How does this project relate to other current research work or trends in policy and practice?

- Policy makers prefer to engage with a synthesis of knowledge rather than individual research project reports. If the findings of the research project put forward radically new treatment options, you may anticipate some resistance from potential users.
- One of the biggest challenges to research transfer is that users will adopt research findings most easily if the findings match their own preconceived beliefs or worldview. They will be very slow to adopt any findings that don't, such as Indigenous worldviews.

Q4. How can you try to ensure your project achieves an impact?

- Involving potential users is one way. You also need to make sure that the ways you try to communicate with different potential users is suitable for their needs.
- Translating research findings into changes in health policy may require the production of briefing notes, meetings with politicians and public servants, and an action-learning approach to implement change at the level of service provision.

Q5. What are the risks or obstacles to successful research transfer for this project?

- Think about the potential barriers to research transfer relevant to your project. Barriers might include a hostile political climate, or language and cultural differences between researchers, policy makers and community members.
- The creation of a Memorandum of Understanding (MOU) among research participants is a strategy that can be used.

Q6. What are the opportunities which exist around this project to facilitate knowledge translation?

- A strong facilitating factor is the deep desire of researchers and organizations to help communities and to improve the health status and health outcomes of M/FN/I peoples.
- What are the key issues and concepts that the research findings address?
- What are the opportunities to lobby for changes to programs and policies or to create new policies?
- What new strategies can be utilized to address health issues?

Q7. Can capacity development be an outcome of this project?

- Research is a capacity developing activity – by planning carefully you can maximize the opportunities for capacity development for project team members, participants, organizations and communities.
- A fundamental component of community-based research is to develop research capacity ‘within the community’. Researchers must be in place in M/FN/I communities and organizations (e.g. NAHO), as well as in universities, to engage in research and KT.

Q8. What are the dissemination and publication requirements for this project?

- Will it require the publication of a report, a journal article, the production of a video, a series of workshops or a media campaign?

- Will the findings of the research project be published in M/FN/I media, such as newsletters, newspaper, radio, television, journals? This could be at the local, regional, provincial/territorial, national and international levels.
- Will the findings be presented at conferences organized by M/FN/I organizations (NAHO, IAPH-CIHR, Circumpolar Health)?

Q9. How have/will you provide feedback to community organizations or members who participated in the research?

- This is one of the most sensitive areas in Indigenous health research because in the past researchers often did not report back to communities and were seen to be taking community knowledge and giving nothing back.
- Effective engagement with communities and participants is also one of the richest potential areas of learning. NAHO and its Centres provide advice on effective strategies on learning.

Q10. How much will a KT process cost?

- **Make sure you budget for knowledge translation in the project proposal.** Effective strategies for knowledge translation are likely to cost money, and are also very likely to take considerable time to make sure they work.
- Without effective planning and budgeting for research transfer, all the hard work and commitment of organizations and M/FN/I participants in doing the research may be “lost in translation”.

Planning from the first steps of the research process to incorporate KT is fundamental to success. However, at the other end of the spectrum, we must also promote support for the users of the research to have the time to participate in research, review research evidence, and work to ensure that access to relevant evidence and where necessary practical guidelines are available (CAAN, 2004; Fletcher, 2003; Ho et al., 2003).

IMPLEMENTING KT AND OCAP IN ABORIGINAL COMMUNITY-BASED HIV/AIDS RESEARCH

In the body of literature regarding Knowledge Translation there is a significant amount of attention dedicated to theories regarding the utilization of knowledge (Estabrooks et al., 2006; Graham et al., 2006; Landry et al., 2003; Lavis, 2006; Neilson, 2001; Schryer-Roy, 2005; Unit 2, n.d.). Each has a rationale for classifying various levels of research uptake and ‘use’; however, a key element that is not always recognized has been raised by Smylie et al. (2003); “Integration of relevant knowledge translation activities within *the context in which the knowledge is to be applied* thus appears to be an important knowledge translation strategy” (p. 141-42). Therefore, when considering the implementation of KT and OCAP in research that involves the Aboriginal AIDS movement in Canada it is imperative to reflect on the context of the various stakeholders (CAAN, 2005a, 2004, 2003). As researchers and/or participants in research, most Aboriginal AIDS initiatives are under funded and staffed by highly dedicated and overworked employees (CAAN, 2005b, 2004). This context may seem daunting for research, and in some cases it is. Some organizations simply do not feel they have the time to engage in a research project (CAAN, 2005b, 2004). For those that do undertake research however, there is an opportunity to use very creative methods to translate knowledge in a way that others can absorb and act upon (Masching et al., 2006; Reading, 2005; Willms et al., 2004).

CAAN is a leader in Aboriginal community-based HIV/AIDS research in Canada (CAAN, 2005a). As described in a recent oral presentation at the 2006 Canadian Association for HIV Research Conference (Masching et al., 2006), the research project “Diagnosis and Care of HIV in Canadian Aboriginal Youth” has emphasized KT

throughout the research process. In 2003, CAAN partnered with academic and government researchers to better understand the HIV testing behaviours and experiences of Aboriginal youth. From conception, KT activities were implemented to facilitate the uptake of research findings by the communities involved, and by various levels of decision-makers. Aboriginal researchers were full partners in the planning, development and implementation of the research project; Aboriginal community members assisted with the design of data collection tools and data collection; capacity building workshops were held; and preliminary findings were presented in a dissemination workshop for possible end-users of the research findings such as community members, funders, and decision-makers. Workshop participants were asked to comment on and correct where necessary, the interpretations of findings by the research team. They were then asked to consider further dissemination activities such as what information they would like disseminated and in what form the information would be best delivered. The full impact of this initiative has not yet been evaluated; however, an array of possible end-users, including decision-makers at the community and national level have expressed interest in the results.

Another example of KT in Aboriginal HIV/AIDS research comes from collaborations between researchers at McMaster University and an unnamed Ontario First Nation (Majumdar et al., 2004). The study was designed to deliver and evaluate a culturally appropriate HIV/AIDS education program for Aboriginal youth that was facilitated by members of the First Nation community. In accordance with principles of KT, care was taken to meaningfully involve community in all stages of project development; opportunities for capacity building were built in to the project; information was delivered by community members; and the study was grounded in the context and concerns of the community in question. In short, the uptake of information by the community was encouraged by incorporating KT activities into the project plan. Results showed that there was “a statistically significant increase in the level of knowledge about HIV/AIDS among participants after completing the culturally sensitive AIDS education training with Aboriginal peer facilitators” (Majumdar et al., 2004, p. 70).

A slightly older but no less valuable example of KT in action involved a project to increase the uptake of HIV/AIDS information by Inuit (Armstrong, 2000). Pauktuutit Inuit Women’s Association of Canada collaborated with Inuit communities to produce culturally appropriate HIV/AIDS prevention materials that were then translated into one dialect of Inuktitut. The project involved extensive community consultations, a three-day HIV/AIDS/STI training workshop in Iqaluit, and on-going collaborations with community representatives. Careful planning for KT from the outset and an openness to community concerns and interests during the project increased community ‘buy-in’ and ultimately helped in the uptake of information.

Other examples of effective KT initiatives can be found from Australia where the Indigenous HealthInfoNet (an Indigenous Health Internet website), a virtual library or web-based database has been created. This website includes “relevant policies and strategies, case studies, details of recent published and other resources, preventive and clinical guidelines, selected and general bibliographic information, and details of organizations involved in the specific area” (Australian Indigenous HealthInfoNet, n.d.). In addition to written resources, a network of consultants provides peer review for new content on the site and contributes to the development of new materials. NAHO has created a similar Website in Canada, the Information Centre on Aboriginal Health (ICAH) (www.ica.hk). ICAH is a virtual library or web-based database of Aboriginal health information; a database of information on bibliographic and internet-based resources, programs and services, health careers, and scholarships and bursaries.

TAKING ACTION

After all of the hard work is done collecting and analyzing data, sharing findings is the final stage of a research project journey (Friedman et al., 2006). There are many methods for disseminating information (Andreasen, 2006; Clarke et al., 2005). The beauty of KT is that all methods are valuable and creativity is encouraged. Implementing KT supports the research team to demonstrate innovation in reaching out to diverse audiences within the community where the research has occurred and beyond to external stakeholders (CIHR, 2006a, 2006b).

Beyond the descriptions already provided, Knowledge Translation can take many forms: journal or newsletter publications, information on a website (e.g. ICAH www.icaah.ca) or in the mass media, direct mailings of results to intended audiences, workshops and conferences, specific meetings with opinion leaders, audit and feedback or reminder procedures, and administrative or economic interventions, stories, songs and other artistic forms of expression, narrative review, systematic review, meta-analysis, meta-database, inventory of best practices, and public health observatory, executive summaries and/or entire final reports translated into the local languages (Choi, 2005; Fletcher, 2003; Martin et al., 2005; Unit 2, n.d.). In addition, “as part of the ‘infostructure’, Telehealth and E-Health are bringing health resources, information, services and personnel to remote and isolated communities. These represent alternative and innovative tools for bridging health and geographic location” (NAHO, 2001, p. 17-18). Ideally, one would also have the opportunity to bridge the gap that often exists between decision makers and researchers by partnering with “‘policy entrepreneurs’ as ‘specialists who are actively promoting changes or shifts in policy to decision makers’” (Williams et al, 2005, p. 297).

Social marketing is another technique that can be used in Knowledge Translation to support action. In social marketing, the primary focus is on the consumer – on learning what people want and need rather than trying to persuade them to buy into what we are producing (Andreasen, 2006; Grier & Bryant, 2005). Applying the principles of social marketing leads researchers, population health professionals and organizations to learn to listen to the needs and desires of target populations themselves, and build a program or research project directed from the community and people. This requires the consumers of research, community organizations and members, to have input into the research process. The success of this approach is shown in recent articles on HIV/AIDS prevention by community intervention in inner city communities in the United States and Africa (Indyk & Rier, 2005; Willms et al., 2004).

Choi (2005) also highlights ‘marketing’ research implications to various audiences. He reasons that “information must be simplified to a level that can be understood and used by the users” (Choi, 2005, p. 93). Using the example of tobacco control for policy makers, the economic and health burden on society is understandable. For youth, messages that smoking will make you ugly and cause premature aging would have an impact. In a similar approach Fletcher (2003) suggests looking for “local idioms and metaphors that provide grounded examples of the information collected through the research” (p. 51). Use local information sources to share information and seek input from a community translator who can help to share information in a “cultural and linguistic form familiar to the communities” (ibid), thereby enhancing uptake.

EVALUATION AND FUTURE POSSIBILITIES

How do we know that the KT approaches we have used actually worked? Various evaluation tactics can be applied to measure uptake and change in the community over time. Examples include: pre/post questionnaires to show if understanding about a topic has increased, report cards to evaluate the integration of research into policy, and citations and references to the final research reports and publications as indicators that the knowledge is being taken up by others.

A central theme throughout the key concepts discussed in this paper – Knowledge Translation, OCAP, community-based research – is the expectation of community involvement. Each of these concepts is strengthened by partnerships between researchers (from the community or from away) and community stakeholders (Kowal, Anderson & Ballie, 2005). The reality of this approach is that developing a process for working together can take time. The end result however has been consistently demonstrated to be more meaningful and more relevant research (Kowal et al., 2005). Kenny (2004) consolidates this notion in the following observation: “the direct input of the people is crucial in designing and implementing policies that work, because the expression of these policies in funding and services are usually the responsibility of grass-roots Aboriginal workers in the communities” (p. 19).

Our understanding of the potential of KT is evolving, at the same time, KT techniques have already been implemented within Aboriginal communities (Allard, 2006; Elias & O’Neil, 2006; Majumdar et al., 2004;

Martin et al., 2005; Smylie et al., 2003, 2006). Certainly, the need exists to bridge and transfer research results to audiences who can benefit from new knowledge produced by Aboriginal HIV/AIDS research. The Aboriginal community as a whole has a strong oral history which is central to the sharing of knowledge and stories are often used to translate meaning to the listener. This is a solid history to build upon.

CONCLUSIONS

Knowledge Translation is a relatively new concept in practice and in literature (Estabrooks et al., 2006; Graham et al., 2006; Lavis, 2006). The literature review prepared by Neilson (2001) offers an excellent summary of the theories of research utilization and models of Knowledge Translation that are currently in use. KT outlines clear expectations for a shift in research accountability from the halls of the academy to the streets of the community with an emphasis on the relevant dissemination of research findings to a wide range of stakeholders who could be considered the end users of the results (Kowal et al., 2005).

Within the Aboriginal community the concept of KT merges easily with the philosophy of OCAP. Both of these perspectives share a practical application that revolves around high levels of community involvement which results in enhanced research outcomes. Both KT and OCAP have the potential to carry health research forward in exciting new directions by building a new level of understanding between the researcher and the research subjects.

Indigenous Peoples around the world are also taking up the challenge to reclaim ownership of their traditional knowledge and develop standards of research for and with their peoples (CAAN, 2005a, 2004, 2003; Kowal et al., 2005; Smith, 1999). Aboriginal participation in every aspect of the health research process is recognized as an important element of Aboriginal research projects that aim to improve Aboriginal health, whether in the Aboriginal community, university, research institute or government. Truly this is a dynamic moment in time for health research and if we are able to achieve our lofty goals of increasing the impact of research results, the health and well being of our societies will certainly be enriched.

REFERENCES

- Allard, Y.E. (2006, March). *Knowledge Translation Toolkit: Questions to be addressed regarding KT in research projects (presentation slides and notes)*. A presentation at the Indigenous Knowledge Translation Summit, March 2 – 5, 2006, First Nations University of Canada, Regina, Saskatchewan. NAHO.
- Andreasen, A.R. (2006). *Social marketing in the 21st century*. Thousand Oaks, Calif. Sage Publications.
- Armstrong, T. (2000). Celebrating Community Knowledge, Encouraging Involvement, Achieving Ownership and Building Confidence Through Comprehensive Community Consultation. *Native Social Work Journal*, 3(1), 107- 117.
- Australian Indigenous HealthInfoNet. (Australian Indigenous Internet site, Edith Cowan University, Perth, Australia). Accessed May 8, 2006. <http://www.healthinonet.ecu.edu.au/frames.htm>
- Bowen S., & Martens P.J. (2005). Demystifying knowledge translation: learning from the community. *J. Health Services Research Policy*. 10(4), 203-211.
- Canadian Aboriginal AIDS Network. (2005a). "Canadian Aboriginal AIDS Network Strategic Plan, 2005-2010." Prepared by Kishk Anaquot Health Research. Ottawa, Ontario: Author.
- Canadian Aboriginal AIDS Network. (2005b). The Canadian Aboriginal AIDS Network's Programs and Activities: An Integrated Evaluation, 2004-2005. Prepared for CAAN by Archibald Consulting. Ottawa, Ontario: Author.

- Canadian Aboriginal AIDS Network. CAAN (2004). Final Report. The community based HIV/AIDS research environmental scan. Available at: <http://www.caan.ca/english/grfx/resources/publications/CAAN>
- Canadian Aboriginal AIDS Network. (2003). "Strengthening Ties - Strengthening Communities. An Aboriginal Strategy on HIV/AIDS in Canada for First Nations, Inuit and Métis People." Ottawa: Author.
- Canadian Aboriginal AIDS Network. (2002a). Ownership, Control, Access and Possession Fact Sheet. Ottawa, Ontario: Author.
- Canadian Aboriginal AIDS Network. (2002b). Principles of Research Collaboration. CAAN, Ottawa, Ontario. Policy template available at <http://www.linkup-connexion.ca>.
- Canadian Institutes of Health Research (CIHR). (2004). *Knowledge Translation Strategy 2004 – 2009: Innovation in Action*. Retrieved February, 24, 2006 from <http://www.cihr-irsc.gc.ca/e/26574.html>.
- Canadian Institutes of Health Research (CIHR) – Institute of Health Services and Policy Research. (2006a). *Evidence in Action, Acting on Evidence. A casebook of health services and policy research knowledge translation stories*. Ottawa. Retrieved June, 6, 2006 from: http://www.cihr-irsc.gc.ca/e/documents/ihspr_ktcasebook_e.pdf
- Canadian Institutes of Health Research (CIHR) – Institute of Population and Public Health, Canadian Public Health Initiative. (2006b). *Moving Population and Public Health Knowledge into Action. A casebook of knowledge translation stories*. Ottawa. Retrieved June, 6, 2006 from: http://www.cihr-irsc.gc.ca/e/documents/ipph_ktcasebook_e.pdf
- Choi, Bernard C.K. (2005). Understanding the Basic Principles of Knowledge Translation. *Journal of Epidemiology and Community Health*. 59, p.93.
- Clarke J.N., Friedman D.B., and Hoffman-Goetz L. (2005). Canadian Aboriginal people's experiences with HIV/AIDS as portrayed in selected English language Aboriginal media (1996-2000). *Social Science & Medicine* 60, 2169-2180.
- Elias B., & O'Neil J. (2006). The Manitoba First Nation Centre for Aboriginal Health research: Knowledge Translation with Indigenous communities. *HealthCare Policy*, 1(4).
- Estabrooks C.A., Thompson D.S., Lovely J.J., & Hofmeyer A. (2006). A guide to knowledge translation theory. *J. Contin. Educ. Health Prof.* 26(1), 25-36.
- Fletcher, C. (2003). Community-based Participatory Research Relationships with Aboriginal Communities in Canada: An Overview of the context and process. *Pimatziwin: A Journal of Aboriginal and Indigenous Community Health*. 1(1), 27-62. ACADRE, University of Alberta.
- Friedman D.J., Parrish R.G., Moiduddin A., & Ketchel A.E. (2005). Health statistics and knowledge creation. Chapter 10, 243-277 in *Health Statistics. Shaping policy and practice to improve the population's health*. Eds. Friedman D.J., Hunter E.L., and Parrish II R.G. Oxford University Press Inc.
- Graham I.D., Logan J., Harrison M.B., Straus S.E., Tetroe J., Caswell W., & Robinson N. (2006). Lost in Knowledge Translation: Time for a map? *J. Contin. Educ. Health Prof.* 26(1), 13-24.
- Grier S., & Bryant C.A. (2005). Social marketing in public health. 26, 319-339. *Annu. Rev. Public Health*. Annual Reviews.

- Grimshaw J.M., Santesco N., Cumpton M., Mayhew A., & McGowan J. (2006). Knowledge for knowledge translation: The role of the Cochrane Collaboration. *J. Contin. Educ. Health Prof.* 26(1), 55-62.
- Ho, K., Lauscher, H.N., Best, A., Walsh, G., Jarvis-Selinger, S., Fedeles, M., & Chockalingam, A. (2004). Dissecting technology-enabled knowledge translation: essential challenges, unprecedented opportunities. *Clinical and Investigative Medicine*, 27(2), 70-78.
- Ho, K., Chockalingam, A., Best, A., & Walsh, G. (2003). Technology-enabled knowledge translation: Building a framework for collaboration. *Canadian Medical Association Journal*, 168(6), 710-711.
- Ibanez-Carrasco F. (2004). CBR: Luxury or Necessity? An environmental scan of the British Columbia Community Based Research Capacity Building needs, capacities and challenges. Community-Based Research Capacity Building Program, British Columbia Persons with AIDS Society. http://www.bcpwa.org/articles/cbr_scan.pdf
- Indyk D., & Rier D.A. (2005). Requisites, benefits, and challenges of sustainable HIV/AIDS system-building where theory meets practice. *Soc. Work Health Care* 42(3-4), 93-110.
- Kenny, C. (2004). A Holistic Framework for Aboriginal Policy Research. Status of Women of Canada. Retrieved February, 24, 2006 from http://www.swc-cfc.gc.ca/pubs/pubspr/0662379594/index_e.html.
- Kowal E., Anderson I., & Ballie R. (2005). Moving beyond good intentions: Indigenous participation in Aboriginal and Torres Strait Islander health research. *Australian N. Z. J. Public Health*, 29, 468-470.
- Landry R., Lamari M., & Amara N. (2003). The extent and determinants of the utilization of university research in government agencies. *Public Administration Review*; 63(2); 192 – 205.
- Lavis J.N. (2006). Research, public policymaking, and knowledge-translation processes: Canadian efforts to build bridges. *J. Contin. Educ. Health Prof.* 26(1), 37-45.
- Macaulay A.C., Cargo M., Bisset S., Delormier T., Lévesque L., Potvin L., & McComber A. (2006). Community Empowerment for the Primary Prevention of Type 2 Diabetes: Kanien'keha:ka (Mohawk) Ways for the Kahnawake Schools Diabetes Prevention Project. In, Ferreira, M.L. and Lang, G.C. *Indigenous Peoples and Diabetes: Community Empowerment and Wellness*. Durham, NC: Carolina Academic Press. Pp.407-458.
- Majumdar, B., Chambers, T., & Roberts, J. (2004). Community-Based, Culturally Sensitive HIV/AIDS Education for Aboriginal Adolescents: Implications for Nursing Practice. *Journal of Transcultural Nursing*, 15(1), 69-73.
- Masching, R., Prentice, T., Allard, Y., Jackson, R., & Mill, J. (May, 2006). Walking the talk: One example of knowledge translation in Aboriginal community-based HIV/AIDS research. Paper presentation at the 14th *Annual Canadian Conference on HIV/AIDS Research*, Quebec City, Quebec. (abstract).
- Martin, D., MacAulay, A., McComber, A., Moore, C., & Wien, F. (2005). *Knowledge Translation: A Quest for Understanding*. Interim Report prepared by the Atlantic Aboriginal Health Research Program and the Kahnawake Schools Diabetes Prevention Project. Halifax: Dalhousie University.
- Mi'kmaq College Institute. (1999). *Mi'kmaq Research Principles and Protocols*. Retrieved June 8, 2006 from <http://mrc.uccb.ns.ca/prinpro.html>.

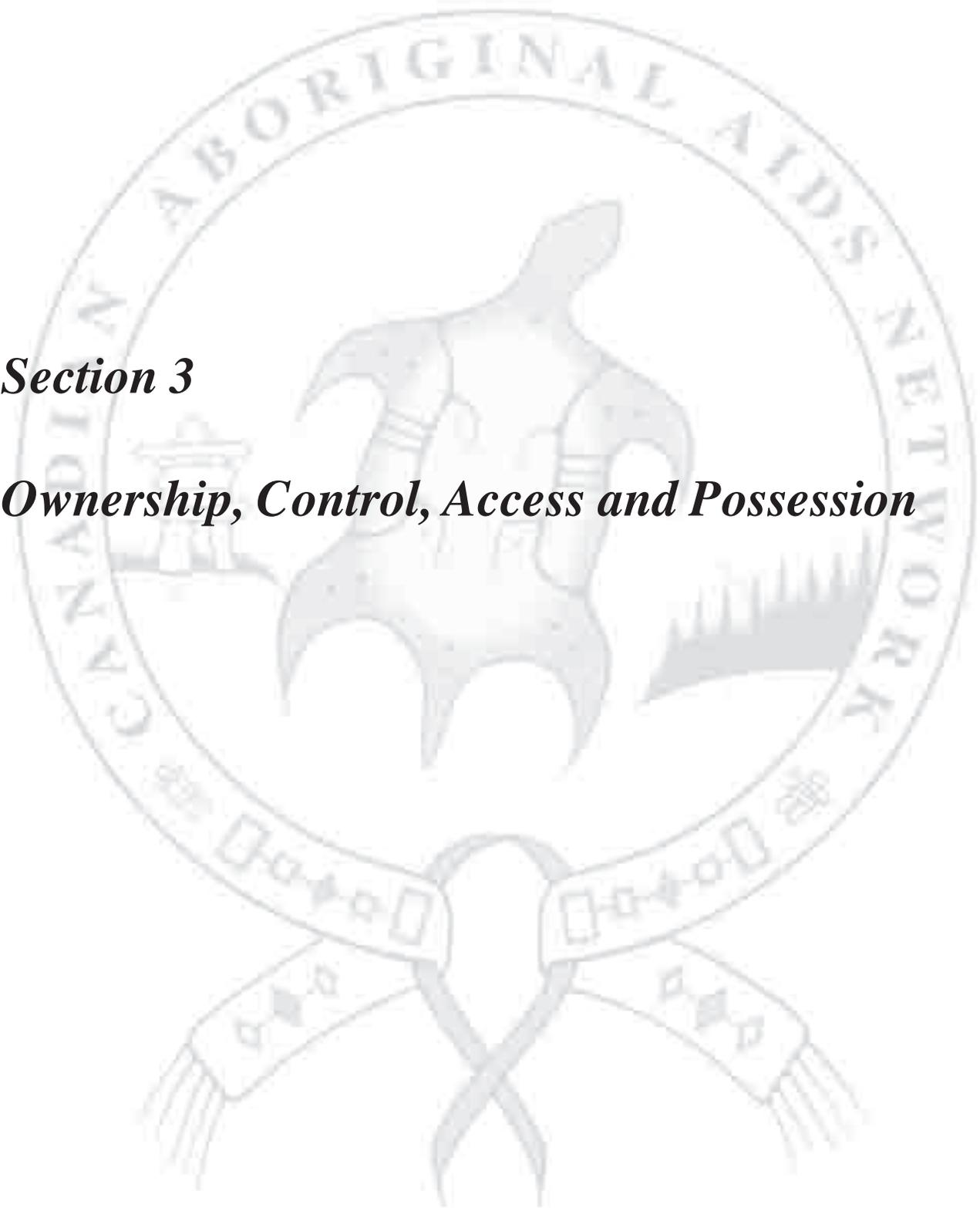
- National Aboriginal Health Organization (NAHO). (2001) *Strategic Directions for an Evidence-Based Decision Making Framework at NAHO*. Retrieved February, 24, 2006 from http://16016.vws.magma.ca/english/pdf/research_strategic.pdf.
- National Centre for the Dissemination of Disability Research. (2005). *Focus: What is Knowledge Translation?* Technical Brief Number 10. Retrieved February, 24, 2006 from <http://www.ncddr.org/du/products/focus/focus10>.
- Neilson, S. (2001). IDRC-Supported Research and its Influence on Public Policy: Knowledge Utilization and Public Policy Processes: A Literature Review. Retrieved February, 24, 2006 from http://www.idrc.ca/en/ev-12186-201-1-DO_TOPIC.html.
- Noojmowin Teg Health Centre. (2003). *Guidelines for Ethical Aboriginal Research: A Resource Manual for the Development of Ethical and Culturally Appropriate Community-based Research Within the First Nations Communities in the Manitoulin Area*. [Community Manual]. Little Current, ON: Author.
- Potvin, L., Cargo, M., McComber, A.M., Delormier, T., & Macaulay, A. (2003). Implementing participatory intervention and research in communities: lessons from the Kahnawake Schools Diabetes Prevention Project in Canada. *Social Science & Medicine*, 56, 1295–1305
- Public Health Agency of Canada. (2005). HIV/AIDS Epi Updates, May 2005, Surveillance and Risk Assessment Division, Centre for Infectious Disease Prevention and Control, Public Health Agency of Canada.
- Reading J. (2005). Foreword from the CIHR Institute of Aboriginal Peoples' Health IAPH. *Canadian Journal of Public Health*, 96 (supplement 1), S8.
- Schnarch, B. (2004). Ownership, Control, Access and Possession (OCAP) or Self-Determination Applied to Research. *Journal of Aboriginal Health*. 1(1): 80-95.
- Schryer-Roy, A.M. (2005) *Knowledge Translation: Basic Theories, Approaches and Applications*. Retrieved February, 24, 2006 from http://www.idrc.ca/uploads/user-S/11303578541Knowledge_Translation_Basic_Theories,_Approaches_and_Applications.pdf
- Smith, L.T. (1999). *Decolonizing methodologies: Research and indigenous peoples*. London: Zed Books.
- Smylie, J., Martin, C.M., Kaplan-Myrth, N., Steele, L., Tait, C., & Hogg, W. (2003). Knowledge Translation and Indigenous Knowledge. *Circumpolar Health* • Nuuk, 139-143.
- Smylie J., McShane K., Martin C., Prince C., Tait C., Kaplan-Myrth N., Valaskakis G., Tugwell P., and Inuit Family Resource Centre, Metis Nation of Ontario, Pikwakanagan First Nation. (May 2006). Understanding effective public health practice in Indigenous community contexts. 97th Annual Conference, Canadian Public Health Association, Vancouver, B.C. (abstract).
- Stephens, C., Porter, J., Nettleton, C., & Willis, R. (2006). Indigenous Health 4: Disappearing, displaced, and undervalued: a call to action for Indigenous health worldwide. *Lancet*. 367, 2019-28.
- Stirling L., & Bisby M. (2006). Translating a Broad Term into Real-World Applications: CIHR's successful approach to knowledge translation. *HealthCare Quarterly*. 9(2), 18-20.
- Williams, A., Labonte, R., Randall, J.E., & Muhajarine, N. (2005). Establishing and sustaining community-university partnerships: A case study of quality of life research. *Critical Public Health*. 15(3): 291–302.

Willms, D., Arratia, M., & Makondesa, P. (2004). Malawi faith communities responding to HIV/AIDS: preliminary findings of a knowledge translation and participatory-action research (PAR) project. *African Journal of AIDS Research*, 3(1), 23-32.

Unit 2. (n.d.) Knowledge Translation: Using Knowledge for Policy, Practice and Action. Retrieved from the World Wide Web February, 24, 2006 using search engine Google. Questions on KT to ask in Aboriginal Community-based Research Projects (Allard 2006)

Section 3

Ownership, Control, Access and Possession



Ethics in Aboriginal Research: Comments on Paradigms, Process and Two Worlds

Mike Patterson¹, Randy Jackson² and Nancy Edwards³

ACKNOWLEDGEMENTS

The authors wish to thank the following people for their help in preparation of this article: Dr. Donna Lockett, Research Associate at the Community Health Research Unit, University of Ottawa; Lisa Dixon MSW (Heiltsuk First Nation), Department of Indian and Northern Affairs; Dr. Simon Brascoupé (Mohawk/Anishnawbe), Professor, Carleton and Trent Universities; and Craig McNaughton of the Social Sciences and Humanities Research Council and Thérèse De Groot of the Interagency Secretariat on Research Ethics, both of whom are key facilitators in the continuing dialogue on Aboriginal ethics.

Dr. Patterson (Métis) is a Canadian Health Services Research Foundation postdoctoral fellow at the School of Nursing and Community Health Research Unit, University of Ottawa. He developed a course on Aboriginal Health at the Institute for Population Health, and has been working in community research and development for 15 years in areas as diverse as Native music, falls prevention with elders, and HIV/AIDS. Randy Jackson (First Nations), is Director of National Research and Programs, Canadian Aboriginal AIDS Network, and has been involved in the Aboriginal HIV movement for 12 years, including community based research. Dr. Edwards is a professor, School of Nursing and Department of Epidemiology and Community Medicine, University of Ottawa. She holds a Nursing Chair funded by the Canadian Health Services Foundation, the Canadian Institutes of Health Research and the Government of Ontario.

ABSTRACT

There is emerging agreement that research with Aboriginal peoples⁴ and communities must involve both the researcher and community in a reflexive process of negotiation, and must build research/community capacity for research. This shift reflects a move from deductive, empirical university and academia-driven models to a more holistic, community action-oriented approach that is Aboriginal-driven. The research is often participatory, inductive and qualitative in nature, calling for flexible research ethics board (REB) procedures. This paper examines these new protocols, and documents some recent researcher experience with communities, research funding bodies and university/hospital/government REBs.

BACKGROUND

This article was produced from the experiences of the authors, and by a review of Aboriginal ethics and community based research literature. Of some 100 protocols and articles produced over the last 20 years in Canada and

¹ Canadian Health Services Research Foundation Postdoctoral Fellow, School of Nursing, University of Ottawa, c/o Community Health Research Unit, 451 Smyth Road Unit 1118D Ottawa ON K1H 8M5, 613-562-5800 X8658, Fax: 613-562-5658, MPatterson@mail.health.uottawa.ca, <http://www.carlton.ca/~mpatters>

² Director of National Research and Programs, Canadian Aboriginal AIDS Network, 602-251 Bank Street, Ottawa, Ontario, K2P 1X3, 1817-1817-1817, Fax: 613-567-4652, randyj@caan.ca

³ Professor, School of Nursing and Department of Epidemiology and Community Medicine, University of Ottawa, CHSRF/CIHR Nursing Chair Director, Community Health Research Unit, 451 Smyth Road, Unit 1118, Ottawa ON K1H 8M5, 613-562-5800 X8395, Fax: 613-562-5658, nedwards@uottawa.ca

⁴ The term 'Aboriginal' includes Inuit, Métis and First Nation (both Status and non-Status) peoples. It reflects an incredible diversity of languages, culture, values and worldview. Our use of the term also includes the concept of 'Indigenous' as being "the tribal peoples [...] whose distinctive identity, values, and history distinguishes them from other sections of the national community, [who] despite their legal status, retain some or all of their social, economic, cultural and political institutions" (Ermine et al., 2004, p. 5).

the U. S., there are many common themes, echoed today in leading topics of discussion and debate involving research, ethics, and Aboriginal communities. It is written primarily as personal reflections on researcher experiences moving between community and academic worlds – practical applications of the principles found in the ‘new’ Aboriginal research ethics.

There is a persistent form of divergence, an alienating tension, at times bordering on animosity, that tarnishes and hangs like a dark cloud over the precarious relationship between Indigenous Peoples and the Western world [...] The schism continually reminds us of the anguished legacy of the Indigenous/West confluence that festers in a convoluted entanglement between the two worlds leading to the failure of arriving at a mutual and amiable meeting of minds [...] The cultural tensions looming over the Indigenous/West relations, in their historical dimension, are particularly magnified on the contested ground of knowledge production and in particular its flagship enterprise of research. Willie Ermine, Ethicist, Indigenous Peoples Health Centre (Ermine, 1995, p.1).

In its 2002 brief, “Governance of Research Involving Human Subjects,” Canada’s National Aboriginal Health Organization (NAHO) points out that: “Research has often had ambiguous qualities for Aboriginal people. Some Aboriginal individuals and communities have been ‘subjects’ of research that has resulted in variable outcomes; some positive, some negative and some with both outcomes” (NAHO, 2002, p. 3). More bluntly, as voiced by the Assembly of First Nations (AFN), “Aboriginal communities have been ‘researched to death’ with few positive outcomes or improvements in their communities” (AFN, 2001, p. 8).

Today, in keeping with current movements toward self-determination in Canada, Aboriginal and non-Aboriginal groups are now looking at new ways of defining Aboriginal research protocols. Aboriginal interests are currently geared towards surviving and thriving through self-determination and control over resources including cultural and knowledge resources [...] the result of the decolonization agenda that has as a principle goal, the amelioration of disease and the recovery of health and wellness for Indigenous populations (Ermine et al., 2004, p. 6).

This is reflected in a 2002 brief from the Saskatchewan Indian Federated College (now First Nations University) recognizing the need for a “paradigm shift” in Aboriginal research ethics. This brief opens with the observation that the Royal Commission on Aboriginal Peoples and the Tri-Council (Social Sciences and Humanities Research Council, National Science and Engineering Research Council, and Canadian Institutes for Health Research)

Agree that a significant element of the solution [to the costs of social problems facing Indigenous peoples] is the need to shift the research paradigm from one in which outsiders seek solutions to ‘the Indian problem’ to one in which Indigenous people conduct research and facilitate solutions themselves.⁵

An example is the Canadian Aboriginal AIDS Network (CAAN), a national HIV/AIDS Aboriginal organization that represents over 200 organizations (including some 150 Aboriginal AIDS Service Organizations (AASOS) across the country, at local and regional levels) and individuals. CAAN has been involved in community-based research (CBR) for at least 10 years and this involvement has, since the beginning, been guided by the right of self-determination and control over the research process. Today CAAN is involved in a number of research projects ranging from issues of mental health (i.e., the experience of depression), to HIV testing for Aboriginal

⁵ “The revision of Section 6, ‘Research involving Aboriginal Peoples,’ of the Tri-Council Policy Statement: Ethical Conduct for research Involving Humans (TCPS) was undertaken by the Interagency Advisory Panel on Research Ethics (PRE) in 2003. It is based on principles of open, inclusive and participatory public processes, engaging Aboriginal peoples and the research community, drawing on diverse disciplines and cultural approaches, fostering constructive collaborations and partnerships while building on international, national and local models (e.g. especially those respectful of Aboriginal knowledge, methodologies and communities)” (personal communication, Thérèse De Groote, PRE, June 2006). Membership in the consortium includes five national Aboriginal organizations as well as the three granting agencies, and PRE. This TCPS initiative will build on parallel initiatives such as the CIHR “Guidelines for Health Research Involving Aboriginal Peoples” written by its Aboriginal Ethics Working Group comprised of Indigenous scholars who are also community people.

youth, to the experience of stigma and the importance of cultural competence in service provision. The goals of these research efforts include providing information and resources to communities to effectively respond to the HIV epidemic in Aboriginal communities. In the context of this research involvement, issues of ethics have been at the forefront, including how best to balance cultural needs and perspectives against the requirements of research ethics boards (REBs). CAAN's involvement in research seeks to contribute to Aboriginal community efforts in preparing an effective response to HIV/AIDS in Aboriginal communities, including influencing evidence-based approaches to both programs and policy.

Working with Aboriginal peoples and communities should involve the researcher and community in a reflexive process of negotiation, and build community capacity for research. This shift reflects a move from deductive, empirical university and academia-driven models to a more holistic, community action-oriented approach to research that is Aboriginal-driven and takes into account the uniqueness of each community.⁶ The central notion here is the diversity of Aboriginal communities, and of types of communities (such as those served by AASOs in cities and on reserves).

There has been some ambivalence around the need for national ethics guidelines. There has been some sense that the solution may lie in creating effective research protocols at the local level, because such protocols reflect and respect individual differences in protocol among various Aboriginal peoples (e.g., the Blackfoot emphasize approval by responsible individuals, not community political representatives; in other Aboriginal communities approvals are given by families that are responsible for various kinds of knowledge) (McNaughton & Rock, 2003, p. 11).

Although some have proposed enforceable, national ethics guidelines in Aboriginal research, this may be impossible, given the need for local, community-based ethics requirements.

BRIDGING TWO WORLDS

The new Aboriginal research paradigm calls for an agreement on research protocols between researchers and the community. Specifically, it calls for a research agreement with the community. In practice, researchers are finding this to be *more process than product*. Where Research Ethics Boards (REBs) call for a 'written in stone' plan of action, work in the community involves a constant learning/and changing process that is oral in nature, flexible and open-ended.

The idea of two worlds and worldviews also comes into play in this process, and researchers become experts in knowledge translation and exchange:

REBs need direction in order to appropriately assess research protocols dealing with Aboriginal communities without sacrificing the scholarly value of the research. For REBs that rarely view protocols for community based participatory research, the assistance of not only community representatives and Aboriginal researchers, but also outside experts (familiar with both worlds) is necessary. (Kaufert et al., 2005, p. 82)

As researchers we often find ourselves moving between the communities on many levels, from meetings with council to attending ceremonies and other gatherings, to the concrete world of REBs, and biomedical research ethics.

Mike Patterson: *When doing my MA thesis, I was required by the REB to get written consent from my 'research subjects' (we still used that term then) to quote them. I was dealing largely with Elders, and we met on many levels over the course of many years. They became mentors, advisors, and friends. As I was wrapping up my thesis, I presented the consent forms to a couple of Elders, who refused to*

⁶ Aboriginal-driven often means and includes research that takes into account cultural beliefs, values and practices (e.g., Elder involvement, etc.).

sign. I realized that our relationship was beyond that of researcher/subject, and that the forms were an intrusion. When the university asked for the forms, I explained the situation, provided a list of names, and said they were free to contact these Elders about the nature of our relationship and study. We never heard back from them.

The central question is how best to bridge the world of academia with the more fluid Aboriginal community reality. Accounting for differing perspectives and worldviews often requires flexibility on each side. CAAN has developed a process of negotiation that recognizes the need for a researcher's need for a 'written in stone' plan of action while simultaneously allowing for ongoing dialogue and open communication:

Randy Jackson: CAAN makes it a regular practice to negotiate the research process in writing at the outset, though the written contract itself is entirely amenable to change at any point (i.e., Principles of Research Collaboration. See Appendix A). When first used, and as the research project (i.e., HIV Testing and Care Decisions for Canadian Aboriginal Youth) entered the writing phase, the issue of authorship became more paramount and dominated discussions among research team and advisory committee members. It became apparent that the original written contract would require changes that addressed these concerns. An addendum was negotiated, signed by all parties, and laid the foundation against which authorship could respectfully be addressed. This process was so successful that it continues to be used across all of CAAN's research projects, particularly where research involves university, hospital/or government-based academics who typically are expected to publish in peer review journals.

COMMUNITY CONSIDERATIONS

From an Aboriginal perspective, research ethics and protocols have more to do with doing good for the community, beyond the protection of individual 'subjects,' so researchers must go beyond the standard scientific or medical ethical model to work with Aboriginal communities. Protocols developed by the REBs do not take community involvement into account; for instance they do not call for community input into ethics submissions, and do not include reference to Aboriginal ethical guidelines in their forms.

Mike Patterson: In working on a falls prevention project in a Mohawk community, I fell into a language divide. The university REB wanted to see documents (such as consent forms) translated into the research partners' language. I thought this to be a good idea and wanted also to start translating our guide "First Nations Falls Prevention" (Lockett et. al. 2004) to Mohawk, and so had written this into our funding proposal to the Institute for Aboriginal Peoples Health at CIHR. This was also mentioned in our REB application. Once we started working in the community however, I got an unexpected reaction. The Elders I worked with strongly objected to written translation of their oral language and history. The Elders said they did not read Mohawk and that the same held true for most Elders they knew. At the same time, the REB had approved our ethics package, but was awaiting delivery of the translated consent forms. I was in a difficult position. The research team discussed this and in the end I presented our dilemma to the Elders, who graciously agreed that it would be easiest to have the consent forms translated to satisfy the REB. At our first Focus Group, the Mohawk consent forms were greeted with some confusion (nobody could read them) and a fair bit of laughter. Everyone signed the English forms, but kept the Mohawk forms as a souvenir.

Based on a review of prominent Aboriginal ethical models (some 20 models), and highlighting those by the AFN, NAHO, CAAN, and local Aboriginal communities, we have identified seven key ethical issues which should be considered when conducting research with Aboriginal communities.

GUIDELINES FOR RESEARCHERS/COMMUNITIES

- 1) Although a research project may simultaneously account for academic interest (e.g. the development of theory, etc.), research must ultimately be of benefit to the community (e.g., demonstrated potential to influence policy, practice and personal/community change, etc.). Research projects should be assessed to see if they address community-relevant priority issues. In other words, the research process supports and applies the principle of Aboriginal self-determination.
- 2) Both individual research subjects and the community should be equally involved in all aspects of research. This promotes a holistic view of research where the contributions of Aboriginal community members and academic researchers are of equal value.
- 3) The principles of Ownership, Control, Access and Possession (OCAP) must be negotiated in good faith.⁷ Also, OCAP is a ‘living’ agreement that must be revisited over the life of the project.
- 4) Although all the usual ethical guidelines apply (i.e., confidentiality, risk/benefit, informed consent, etc.), respect for the community and its culture is essential. Ethical consideration need also include the ethic of equal participation and consultation that incorporates local and traditional knowledge.⁸ The nature of the participation by researchers and community members may differ substantially when academic and traditional knowledge come together.
- 5) The reciprocal process of capacity-building is undertaken where academics learn about local and traditional knowledge and Aboriginal needs for capacity-building in community based research are also met.
- 6) The scientific goals of the Project must be respected in this process, along with respect for and inclusion of Aboriginal knowledge (worldview) and methodologies.
- 7) The community should be consulted when research questions and protocols are being developed, when data is collected and analyzed, and when findings are generated. They should also be given ample opportunity for feedback and participation in the dissemination of research findings. Community input is also critical in developing knowledge translation strategies that are meaningful and appropriate to the audience, whether academic or community, for successful uptake of research results.

If research is first proposed by academics, the research process should be made clear to the community, so that the project can be assessed to see if it addresses priority issues. Many people need to be involved in this process. As described by Marlene Brant-Castellano, at a Tri-Council Colloquium on Ethics held at the University of Ottawa in Nov. 2003, the researcher can be seen to be negotiating a series of gates, each of which relates to various individuals, organizations or sensitivities (such as cultural) of the community. Each of these gates may have different keepers, including Elders, people who are part of the research itself, the Band Council, or various segments of the community, such as women, veterans, youth, etc.

⁷ “Originally coined as OCA – a more resonant acronym with its nod to the 1990 Oka Crisis – OCAP is changing the way research is done” (Snarch, 2004, pps. 80-81). “CAAN understands OCAP to mean the following: *Ownership* refers to a relationship Aboriginal communities have to collectively possess their cultural knowledge, data and information. Involvement in research does not transfer ownership to any particular individual and does not end following publication. Rather, ownership remains with the collective community through its representatives. *Control* refers to an absolute right to be equally involved in all stages of research, from problem definition through to research finding presentation or publication. *Access* to the resulting data of research is a key feature of OCAP. This applies regardless of where or how resulting data is held. *Possession* refers to the mechanism that respects the concept of ownership. Typically this refers to written agreements that asserts traditional proprietary rights and incorporates cultural values and perspectives” (Barlow, Kevin et. al. 2005).

⁸ “...Indigenous knowledge benchmarks the limitations of Eurocentric theory -- its methodology, evidence, and conclusions -- reconceptualizes the resilience and self-reliance of Indigenous peoples, and underscores the importance of their own philosophies, heritages, and educational processes” (Battiste, 1995, p. 2), “...[It]...is not a uniform concept across all Indigenous peoples; it is a diverse knowledge that is spread throughout different peoples in many layers... Indigenous knowledge is so much a part of the clan, band, or community, or even individual, that it cannot be separated from the bearer to be codified into a [Eurocentric] definition.” Indigenous peoples’ worldviews are cognitive maps of particular ecosystems... Strands of connectiveness do exist, however, among Indigenous thought... [many teachings from North and South America] ...reflect a cultural interpretation based on observation of the processes inherent in nature” (Battiste and Youngblood, 2000, pps. 36-37, 40).

Randy Jackson: *For CAAN research projects, negotiation of access to a research site is typically the responsibility of community members of a research team. Negotiation and preparation of ethical submissions is primarily the responsibility of academics on the team, with input by community. One process used by CAAN in a past research project (i.e., Mental Health) has been having the research design submitted first to a community advisory committee in a language and manner that is appropriate. Only after their comments and feedback are incorporated is a submission to an REB done. As a general guideline, the research process needs to be flexible to accommodate this input and project timelines must allow for this process to occur in a meaningful way.*

The research should be a partnership, or rather, many of them. CAAN, in its Aboriginal Capacity Building Program on Community Based Research (launched with Health Canada and now under CIHR), requires that research subjects and communities “be actively included in all aspects” of research, with Aboriginal participation demonstrated in all stages of the research process, including but not limited to: needs assessments (defining priority individual and community needs); identification of research questions (how best to answer these needs); collecting and analyzing data; and reporting and applying the results. Research processes need also include capacity building, for academics and communities alike.

MAKING IT WORK

Working with OCAP guidelines is a challenge for institutions in particular: The concept of ownership challenges the academic notion of intellectual property; the concept of control challenges the academic notion of academic freedom; and principles guiding community access to research data may be unfamiliar to REBs. With respect to access, REBs are particularly concerned about protecting the confidentiality of research participants and thus, community access to data may be seen as a risky proposition that fails to safeguard confidentiality. However, the OCAP guidelines bring another dimension of access into focus, one that is grounded in the concept of self-determination. That is, the importance of the community having control over not just the data, but also how it is used, and what actions are taken and by whom, in response to the findings. The sensitivity of the research topic may affect discussions regarding data ownership. The community can be questioned about its ability and resource infrastructure to safeguard data, particularly data that has not been cleaned of identifying information.

Randy Jackson: *In negotiating an ethics submission, CAAN encountered a situation where the REB continually made requests for clarification of procedures for the safeguarding of confidential information. Despite our attempts to solve this problem in writing, it took a meeting with a representative of this REB to clarify the importance of retaining community access/ownership of data collected. In the meeting, CAAN representatives spoke to issues that considered the importance of OCAP – this particular REB seems fairly forthcoming and we managed to negotiate a reasonable solution that satisfied all involved. This speaks to the importance of personal meetings in negotiations with REBs, to facilitate their understanding of Aboriginal research ethics. In the end the REB issued an ethics certificate.*

Since each community and research project is different, priorities for the applications of OCAP research guidelines will vary, depending on factors such as the nature of the research, constraints imposed by research funding bodies, or community wishes. In some cases, communities will insist on complete ownership of the research process and results, including rights to publication. Other arrangements may ensure that the community, the researcher, and the academic community will each benefit from the results.

Randy Jackson: *With respect to publication of findings, CAAN’s position is one that can be thought of as joint ownership. The community is always provided reasonable and adequate time to review and respond to draft publications and presentations. In cases of disagreements over interpretation of results, a significant degree of research team consensus is always sought. Where agreements can’t*

be reached, rather than bar a publication or presentation, dissenting opinions may be included in the dissemination of results. This has not happened in any of CAAN's research projects to date.

DRIVING ABORIGINAL COMMUNITY ACTION RESEARCH

The process should also help build capacity for what we propose could be called Aboriginal Community Action Research (ACAR), research initiated and directed by communities themselves. Participatory Action Research (PAR) has historically sought to involve research subjects as participants in a process toward action and positive change, Community-Based Research (CBR) goes a step further by calling for a full equitable partnership between the researchers and the community, building community research capacity and sustainable processes for further research and action. But the Action is missing from CBR; Aboriginal Community Action Research, ACAR, is what is needed to drive community involvement and capacity.

Mike Patterson: When we proposed a project in one community, we first went through a five hour meeting with health professionals there. They were very hesitant to endorse another research project, until I pointed out that this was an "action project," not just research; we wanted to raise awareness about the issues to effect positive change, with help and guidance of the Elders, and also build community capacity for further research. This was when they agreed to work with us.

RIGOROUS, RESPONSIBLE RESEARCH

The call is for culturally appropriate and rigorous, replicable research, analysis, and dissemination strategies that are beneficial to communities, researchers and institutions alike. Visiting researchers should give tools, techniques and training that communities can use themselves, and be better equipped to establish full research partnerships. The community provides researchers with knowledge and skills that serve to increase cultural competence in designing and implementing research projects. In this sense, both sides benefit by having capacity built.

Ethics considerations should be discussed and agreed upon with community leaders, including the Band Council, Elders, health professionals and also the study participants themselves. This should be part of the initial research design, and discussions about ethics should help define the research agenda. As much as possible, the goal should be to reach consensus on both the research objectives, and the ethical application of those in the community.

Mike Patterson: I begin sharing the (anonymized) data with research participants, RAs and other community members early on in our projects, including discussions regarding possible authorship. Through this process, decisions about how to best continue the research are grounded in community experience. People are not always keen to get involved, though. For instance, elected officials and health professionals often do not have time, or interest, to be involved in all projects in the community. Researchers should consider when and how to engage already overworked frontline workers, so as not to strain but to improve community resources.

EXAMPLES OF ABORIGINAL PROTOCOLS

Akwesasne is a leader in the development of Aboriginal research ethics codes. Working with Elders, three Band Councils, universities such as Harvard and the University of Ottawa, and health professionals, the community is constantly defining and refining its ethics priorities. A watershed document was the "Protocol for Review of Environmental and Scientific Research Proposals" (1996), which calls for: "Empowerment" of both researched and researcher through a "good research agreement developed by both the community and the researcher [...] where application of the research as a useful instrument of the community is balanced with the researchers need for good science;" "Equity," which is defined as a sharing of resources: "Both the researchers and the community must bring equity to the agreement... Finance or money is only one form of equity. Community

knowledge, networks, personnel and political/social power are other forms of equity useful to the project;” and “Respect,” meaning that “the researchers and the community must generate respect for each other. Respect is generated by understanding each others social, political and cultural structures... Cultural sensitivity⁹ training for the researchers and community awareness presentations will help develop a mutual understanding of the research process.”

To these the authors would add the concept of trust through effective knowledge transfer: Research processes and procedures must be well explained and understood from a community perspective; not to do so can lead to situations of not trusting the partnership. This can ultimately lead to a slower than normal research process, or an ending of a research partnership agreement.

In Kahnawake, an extensive code of research ethics was developed involving three partners: 1) the community, represented by an advisory board drawn from the local Mohawk hospital and school board; 2) the community researchers themselves; and 3) representatives from two universities. The Kahnawake Schools Diabetes Prevention Project developed its “Code of Research Ethics,” emphasizing that the community is a full partner in all aspects of research, detailing the obligations of academic researchers, community researchers and community partners, and providing authorship guidelines for communicating results to the community and for publication (Kahnawake, 1996).

The “Mi’kmaq Research Principles and Protocols” call for an ethics ‘Watch’ to review “all research conducted among Mi’kmaq people and maintain control over all research processes” (Mi’kmaq Ethics Watch Committee, 2000, ¶6). There is also an extensive list of obligations and protocols for researchers, beginning with the understanding that “All research on Mi’kmaq is to be approached as a negotiated partnership, taking into account all the interests of those who live in the communities. Participants shall be recognized and treated as equals in the research done instead of as ‘informants’ or ‘subjects.’” (¶2) The obligations to researchers also include keeping community members informed in their own language, and delivering research skills to the community where appropriate.

Many First Nations, Inuit and Métis community research models are based on community development, needs assessments, and traditional knowledge methodologies. It is important for outside researchers to understand how communities see and approach research. Community development has been the predominant research approach which centers decision-making at the community level. *A Community Guide to Protecting Indigenous Knowledge* (Brascoupe & Mann, 2001) illustrates how a community development model, which is participatory and utilizes traditional knowledge, can protect a community’s knowledge.

CAAN has also developed its own protocol that is used extensively across all its research projects, whether community initiated or not. This document, *Principles of Research Collaboration*, acknowledges the importance of “incorporating cultural values and perspectives into the research process.” Where the guiding principle is always striving for a significant degree of consensus among research team members, the document outlines the importance of the right to self-determination in research: That Aboriginal participation is meaningfully equal; that the community be involved in the design of a study; that there is a balance between academic/community interests; that ownership of data be shared among members of a research team; and likely most important, the research 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.” It also insists that the ‘Aboriginal problem’ not be sensationalized, but balanced with more positive aspects.

Randy Jackson: Once data is cleaned of identifying information, CAAN also has a process where data is shared with members of a research advisory committee. Members often share important information with respect to interpretation and offer advice with respect to treatment of potentially sensational

⁹ The call today is for cultural competence, not just sensitivity. Being sensitive to another’s culture is one thing – cultural competence is an entire higher level skill set that implies an ability to effectively function in another culture that is not one’s own.

research findings. Beyond this, research advisory committees can and have offered suggestions that guide community dissemination and potentially stimulate research uptake.

CHALLENGES TO THE KNOWLEDGE BROKER

Adherence to the emerging Aboriginal research ethics guidelines will be a challenge, particularly for researchers acting as brokers of knowledge between the two worlds, and among all participants in the circle. First, the process involves a complex set of negotiations among researchers, community members, Elders, Band Councils, institutions and other stakeholders, each with their own protocols and expectations. Those wanting to conduct research in Aboriginal communities will need to consider the interests of all concerned, and develop strategies jointly with the community, which can complicate the REB process. Further complicating this is the fact that there is no consistency among university REBs with regards to issues raised in the OCAP guidelines. As well, enforcement of REBs' existing paradigms is inconsistent from institution to institution, and committee to committee.

With regard to issues above, part of a researchers' job is to sensitize the REB to cultural differences with regard to ethics. It is a daunting task, as the REB relies on its 'institution' of protocols, but the members of ethics committees (the ones to be informed) tend to come and go. REBs need to be made aware of the unique situation of Aboriginal people in Canada. This sensitization is also necessary for those working with other similarly stigmatized or marginalized groups, and experience with new Aboriginal research paradigms may help open the door to this.

Cultural competency should be required to judge Aboriginal research projects. Culturally biased university ethics procedures (i.e. based on Western or Eurocentric worldview, or on biomedical models) cannot serve the Aboriginal communities. In other words, "ethical research must begin by replacing Eurocentric prejudice with new premises that value diversity over universality" (Battiste & Youngblood, 2000, p. 133). Further to this agenda, an improvement would be to see ethics reviews being done by Aboriginal communities with universities offering reciprocity (rather than the other way around), or the development of Aboriginal REBs at universities.

The researcher today must engage in a complex, but rewarding, discussion of needs and perspectives involving key community members, research participants, and health, educational and/or government organizations. This involves research into (and possibly involvement in) the participating community's culture, language and traditions, before the research project proper can commence. It is acknowledging the reality that each Aboriginal community, and each project, is different, and that each situation requires the mutual respect and concern that can only be generated by sharing complimentary cultural differences. We should "engage an ethical space for a dialogue between Indigenous people and Western scientists [using] double-door entry [by receiving] approval from the community as well as the university [through acknowledgement of] Indigenous theory and method" (Battiste, 2006, p. 16).

This decolonizing of the research process on the part of the researchers, communities and REBs promises increased culturally coherent research with richer data and more utility (through the mutually reflexive process), real benefits to the communities involved, and a sharing of knowledge that will enrich all of society. Rather than "research Aboriginal communities to death," it is time for researchers, academics and REBs to support processes that research Aboriginal communities to life.

REFERENCES

- Akwesasne Task Force on the Environment, Research Advisory Committee. (1996). *Protocol for review of environmental and scientific research proposals*. Hogansburg (NY): Akwesasne Task Force on the Environment, Research Advisory Committee.
- Assembly of First Nations. 2001. *Ethics in Aboriginal Research*. Presentation at the AFN Health Conference, First Nations Information Governance Committee, Feb. 26, 2001.
- Barlow, K., Jackson, R., Epale, D., Masching, R., Loppie, C., Akan, M., & George, J. (2005). *Taking OCAP Principles from Theory to Practice: The Formulation of a Research Project Related to Cultural Competence for HIV/AIDS Health Care Providers*. Abstract presented at the Canadian Association of HIV Research. Vancouver, British Columbia.
- Battiste, M. (2006). "Research Involving Indigenous Peoples: Issues for Researchers." Presentation at the World Indigenous People's Conference in Education (Wipce) November 2006, Hamilton, New Zealand. At <http://www.usask.ca/education/people/battistem/wipce.html>. Accessed 10/2/06.
- Battiste, M. (2005). "Perspectives on Indigenous Knowledge" in Indigenous Knowledge 1/1. World Indigenous Nations Higher Education Consortium. At <http://www.win-hec.org/?q=node/34>. Accessed 28/2/06.
- Battiste, M., & Henderson, J.S.Y. (2000). *Protecting Indigenous Knowledge and Heritage: a Global Challenge*. Saskatoon: Purich Press.
- Brant Castellano, M. (2004). Ethics of Aboriginal Research. *Journal of Aboriginal Health*, 1/1, 98-114.
- Brascoupé, S. & Mann, H. (2001). *A Community Guide to Protecting Indigenous Knowledge*. Research and Analysis Directorate, Department of Indian and Northern Development, June 2001
- Canadian Aboriginal AIDS Network. (2003). *Background on Aboriginal Capacity Building Program on Community Based Research*. At http://www.caan.ca/cbr_index.htm. Accessed 15/7/05.
- Ermine, W. (1995). *Ethical Space: Transforming Relations*. Discussion Paper. At http://www.traditions.gc.ca/docs/docs_disc_ermine_e.cfm. Accessed 24/11/05.
- Ermine, W., Sinclair, R. & Jeffery, B. (2004). *The Ethics of Research Involving Indigenous Peoples. Report of the Indigenous Peoples Health Research Centre to the Interagency Advisory Panel on Research Ethics*. Saskatoon: Indigenous Peoples. Health Research Centre. At <http://www.iphrc.ca/text/Ethics%20Review%20IPHRC.pdf>. Accessed 10/1/06. Kahnawake Schools. (1996). *Code of Research Ethics*. Kahnawake Schools Diabetes Prevention Project. Kahnawake, Quebec.
- Kaufert, J., Glass, K., & Freeman, W.L. (2005). *Background Paper on Issues of Group, Community or First Nation Consent in Health Research*. Winnipeg: Manitoba: University of Manitoba, Department of Community Health Sciences. At http://www.umanitoba.ca/centres/cahr/cahr-research/research_publications/research_publications_reports.html. Accessed 4/5/06.
- Lockett, D., Patterson, M., & Dixon, L. (2004). *First Nations Falls Prevention: A Guide for Aboriginal Communities*. Community Health Research Unit, University of Ottawa. Available at <http://aix1.uottawa.ca/%7Eenedwards/chru/english/resources.html>.

McNaughton, C., & Rock, D. (2004). *Opportunities in Aboriginal Research: Results of SSHRC's Dialogue on Research and Aboriginal Peoples*. Ottawa: Social Sciences and Humanities Research Council of Canada (SSHRC). At http://www.sshrc.ca/web/apply/background/aboriginal_backgrounder_e.pdf.

Mi'kmaq Ethics Watch Committee. (2000). *Principles and Guidelines for Researchers Conducting Research With and/or Among Mi'kmaq People*. Mi'kmaq College Institute, at <http://mrc.uccb.ns.ca/prinpro.html>. Accessed 1/1/06.

National Aboriginal Health Organization. (2002). *Governance of Research Involving Human Subjects*. Ottawa: National Aboriginal Health Organization.

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*, 1/1, 80-95.

APPENDIX A

Principles of Research Collaboration

Between
The Canadian Aboriginal AIDS Network
And
[INSERT NAMES]

PARTIES

This document constitutes a Principles for Research Collaboration (PRC) between [INSERT NAMES] (investigators) and the Canadian Aboriginal AIDS Network, a national non-governmental organization dedicated to providing, support and advocacy for Aboriginal People living with and affected by HIV/AIDS regardless of where they reside.

The Canadian Aboriginal AIDS Network will participate as a member of the research team under the terms identified below through [INSERT NAMES].

The above listed individuals constitute the research team. Additional members may join in signing this PRC and participate as members of the research team once all members (listed above) have agreed.

PURPOSE

The purpose of this PRC is to establish a set of principles that guide the conduct of the research projects, “[INSERT PROJECT TITLE]” In short, this agreement acknowledges the importance of incorporating cultural values and perspectives into the research process.

RECORDS

The Principal Investigator (PI) or project coordinator will coordinate all administrative matters relating to the above named research project. The PI or project coordinator will provide each member of the research team with notes of meetings, including decisions made, within a reasonable time frame.

ETHICAL CONSIDERATIONS

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

DURATION AND AMENDMENTS

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

PRINCIPLES: OWNERSHIP, CONTROL, ACCESS AND POSSESSION

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

- Members of the research 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 research team and Aboriginal communities. Further, the research team agrees they will strive to respect the privacy, dignity, culture and rights of Aboriginal peoples.
- The research team will strive to include meaningful and equal participation from Aboriginal community members. Therefore, the parties agree they will be jointly and equally involved from beginning to end in the research process, from research question formulation, through data collection, analysis and into dissemination of research findings related to the above named project.
- The research 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 Canadian Aboriginal AIDS Network.
- The research team agrees that they will collectively make decisions on research questions, in data collection, interpreting results, in drafting research reports and in dissemination of findings. In other words, the PI will not present a completed research design for approval but involve all other members of the research team in the process.
- 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 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 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. two months).
- Given that all members of the research team will be provided the opportunity to review and comment on findings prior to publication or presentation, any one member of the research 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 PI 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 SPSS or QSR*N6 (NUD*IST) computer files may be shared with all members of the research 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 team agrees to provide meaningful and appropriate research capacity-building, as indicated by Aboriginal community participants.

- The research 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 team will strive to resolve conflict towards achieving a significant degree of consensus.
- The research 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 recommends 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,

- Research project staff may participate as authors provided that they fulfill the criteria outlined above.
- All members of the research team will be provided the opportunity to review and comment on findings prior to publication or presentation. Any one member of the research team may further analyse, publish or present findings resulting from the above-mentioned research project with the agreement of the Principal Investigator and the other research 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 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.

IN WITNESS WHEREOF, the parties hereto have executed this agreement.

_____	_____
<i>(Date)</i>	<i>(Signature)</i>
_____	_____
_____	_____
_____	_____

REFERENCES

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.

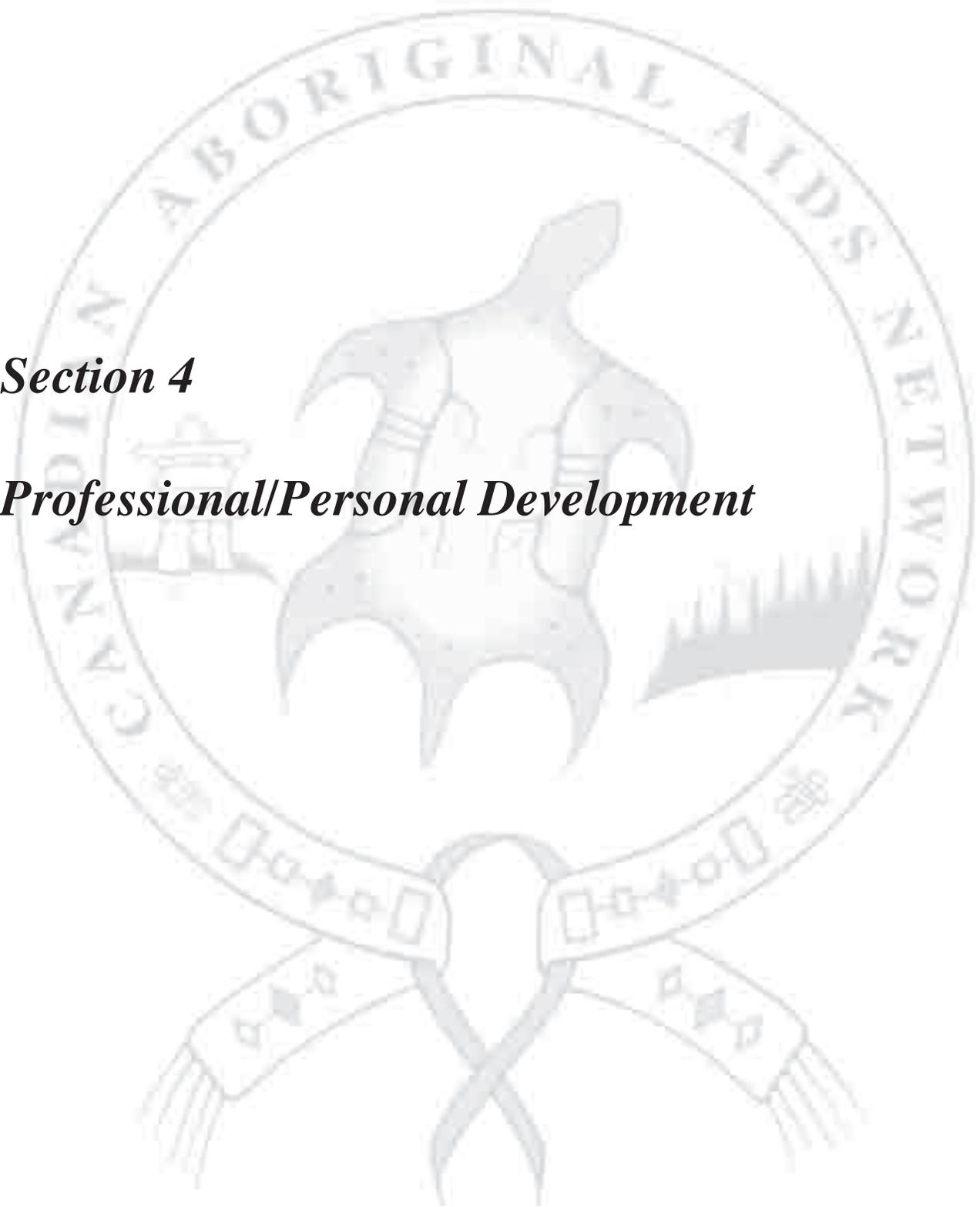
Canadian Aboriginal AIDS Network (2002). *Ownership, Control, Access and Possession Fact Sheet*. Ottawa, Ontario.

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 Elias, 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).

Section 4

Professional/Personal Development



Negotiating Partnership and Ownership in Community-Based Research: Lessons from a Needle Exchange in Montréal

Viviane Namaste¹ and Pascal Jauffret²

ABSTRACT

The field of community-based research (CBR) maintains that members of a research population are to be actively involved in the generation and interpretation of data which concerns them. This paper examines a process for negotiating partnership between a needle exchange programme and institutional researchers in Montréal. The paper outlines some of the reasons why this agency needed to develop guidelines related to partnership and the ownership of research results. The lessons learned can be applied and adapted to different settings, and provide a model for Aboriginal communities to negotiate formal agreements with institutional researchers from universities or public health departments.

BACKGROUND

Historically, the relation between Indigenous people and scientific researchers has been complex and complicated. Scientific research was an integral part of the work of colonization, as demonstrated by Aboriginal scholars (Smith, 1999). These critics clearly show the ways in which the practice of colonialism was often justified in and through 'scientific' theories – the argument that a particular people was uncivilized provided an alibi to conquer them, dispossess them of their lands, language and traditions, and even to kill them outright. Given such a history, then, the stakes are quite high when it comes to doing research on questions related to Aboriginal people.

The complex relations Aboriginal communities have to research itself have been underlined in recent years with controversies related to genetic research and Indigenous knowledge. The initiative Human Genome Diversity Project, for example, seeks to obtain genetic information from Indigenous people all over the globe. Aboriginal people object that the process has in no way involved Indigenous people, and that it further represents a research initiative destined to benefit the interests of pharmaceutical companies, who will profit from the patents obtained on such genetic material (Lone Dog, 1999). Indigenous people will, once again, be mere objects of knowledge. In a similar vein, Indigenous peoples object to researchers using their traditional knowledge of different plants to develop scientific and pharmaceutical remedies whose profits will not benefit the particular Indigenous community from which the knowledge was obtained (Zerda-Sarmiento & Forero-Pineda, 2002). Questions about genetic research and indigenous knowledge, then, are two current examples which illustrate the unequal power relations between scientific researchers and Aboriginal communities.

THE RELEVANCE OF COMMUNITY BASED RESEARCH

Within such a general context in which scientists exploit and objectify Indigenous peoples, the idea and practice of community based research (CBR) is refreshing. CBR refers to a research process in which members of a target population are actively involved, from the development and conception of the research question, to the collection of data, to the interpretation of results, to the dissemination of research findings. CBR can be conducted by academic and institutional researchers if they are committed to a research process which is truly community-based. CBR can also be conducted by a community organization.

¹ Associate Professor, Women's Studies, Simone de Beauvoir Institute, Concordia University, 1455, blvd. de Maisonneuve ouest, Montréal (Québec), H3G 1M8, viviane@alcor.concordia.ca

² Pascal Jauffret is a former street outreach worker with CACTUS-Montreal who currently resides in Marseille, France.

Terry Trussler and Rick Marchand (2000) have outlined ten guiding principles of CBR. These are:

Partnership Initiative	(Equality between the community and professionals)
Peer Review	(Involvement of the population from the beginning)
Community Benefit	(Involvement of the population in the grant review)
Capacity Building	(The research must improve the conditions of the community)
Ownership	(CBR helps people learn how to do research)
Interpretation	(Lived experience belongs to the community. Members have the right to refuse the research results.)
Distribution	(The involvement of the population in the analysis and interpretation of the results.)
Implementation	(The right of the population to revise before publication and to ensure the research is presented in an accessible language.)
Empowerment	(The research should facilitate program delivery and be able to be integrated into services.)
	(CBR should encourage members to initiate their own research projects.)

(p. 38).

Drawing on the framework outlined by Trussler and Marchand, this paper recounts some lessons learned at a needle-exchange in Montréal, CACTUS (Centre d'Action Communautaire auprès des Toxicomanes Utilisateurs de Seringues). The lessons are especially concerned with the principles of *ownership*, *interpretation*, and *distribution*. We begin with a description of different institutional research projects at CACTUS and examine some of the salient issues in terms of CBR. We then outline the steps taken by CACTUS to ensure its equal partnership with institutional researchers. It is hoped that the lessons learned will be relevant to different Aboriginal communities in negotiating partnership with institutional researchers from local universities and/or departments of public health.

It is important to specify that this paper concerns the elaboration of an equal partnership between a community-based organization and institutional researchers. This is a situation somewhat different from one in which a community based organization initiates and conducts a research project on its own. Nevertheless, it raises fundamental questions about the process of conducting research, most particularly with regards to the validation of research results. Furthermore, we underline here that this paper reflects the particular view of its authors. Both authors were staff members of CACTUS-Montréal in 2000, although they have both since moved on to work elsewhere. The statements and interpretations made here do not reflect the official position of CACTUS-Montréal, the individual researchers, the team of researchers discussed in the different examples, nor the Department of Public Health of Montréal. To be consistent with CBR principles, a copy of this article was shared with CACTUS with an opportunity for comment prior to submission for publication.

THREE EXAMPLES OF INSTITUTIONAL RESEARCH AT CACTUS: KNOWLEDGE FOR WHOM?

CACTUS was founded in 1989, the first needle exchange in Canada. The agency was established by concerned individuals working in public health. In recent years, the actions of certain researchers working 'in partnership' with CACTUS have forced some members of the organization to question its involvement in research, and to develop mechanisms to ensure that the perspectives of both the agency and its clients are adequately represented in research findings. Three different instances explain how some workers at CACTUS came to be suspicious of institutional researchers.

The first example is well known. In the fall of 1997, researchers in the field of HIV and intravenous drug use released the results of a cohort study on IDUs in Montréal (Bruneau et al., 1997). The findings revealed that amongst the clientele of CACTUS, there were more seropositive IDUs compared with IDUs who did not use the services of a needle exchange. The researchers maintained that the results of this study raised serious questions

about the universal benefits of needle exchange programs (NEPs): “We believe caution is warranted before accepting NEPs as uniformly beneficial in any setting.” (Bruneau cited in Loconte, 1998). The results and interpretation of the study took many people in the field of HIV and addictions by surprise; workers at CACTUS, other researchers, and even the Department of Public Health. The ‘surprise’ element was augmented by the fact that the researcher had not contacted CACTUS before releasing the results of her study at a press conference. In practical terms, this meant that the agency was in a position of reaction to the media. The Executive Director of CACTUS had to field questions from the media which called into question the very justification and relevance of the program, the Department of Public Health had to rationalize its funding, and workers of the needle exchange had to answer questions from the clientele. The severity of the situation was perhaps most apparent to frontline workers, for example when, one client asked a worker if the media reports meant that CACTUS was giving out dirty needles.

The situation illustrates well how this institutional researcher did not follow the principles of CBR outlined by Trussler and Marchand (2000). In this case, it is clear that CACTUS was not involved as an equal partner in the research process. Indeed, CACTUS offered its own interpretation of the data; if more seropositive people were amongst the clientele of CACTUS than IDUs who did not go to needle exchanges, this could be explained by the fact that CACTUS often served as a bridge to the health care network for IDUs, people who were deeply mistrustful of health services given the discrimination they faced as drug users. In this regard, it is especially important to fund programs like CACTUS precisely because they establish contact and meaningful relationships with the most marginal of seropositive people, and work to hook them up to the existing health care and social services network.³

This experience further demonstrates the importance of involving the community not only in the interpretation of the results, but also in their dissemination. The situation demanded that CACTUS, public health, and everyday IDUs react to this information. This process did not involve members of the population (the principle of *initiative*). Furthermore, subsequent to this event, CACTUS raised an important ethical issue: the release of the research results without consulting CACTUS and IDUs created a context in which confusing or contradictory messages were disseminated in the general public through the mass media. This confusion was most apparent in the question posed to the needle exchange by a user: “Are you giving out dirty needles?” In this regard, the lack of involvement of CACTUS and IDUs in the dissemination of the research damaged the reputation of the organization in the milieu of intravenous drug users. It is important to underline that such credibility is tenuous at the best of times, given the criminalization of drug use in Canada and the subsequent discrimination IDUs experience in health care, housing, and employment. Damaged credibility with this population, then, can easily reinforce a perception of CACTUS as an agency ‘like all the others’, where drug users are not respected and where their involvement is not encouraged or welcome. While the researcher did not have to negotiate this issue in the long term, it remained a central aspect of the everyday work CACTUS could do with IDUs in Montréal.

The second example of institutional research with CACTUS also raises fundamental questions with respect to the credibility of the organization among intravenous drug users. The project in question was a qualitative study of the different kinds of IDUs who use the services of CACTUS, in order to develop appropriate programs of HIV prevention for the population. The researchers conducted interviews with IDUs, as well as engaging in participant observation in both the fixed site needle exchange and on the street with outreach workers.

³ Bruneau’s research has been used in an attempt to oppose needle exchange programs in the United States, and she wrote an editorial in the New York Times which countered the mis-use of her research. See Julie Bruneau and Martin Schechter, “The Politics of Needles and AIDS”, The New York Times, April 9, 1998. Available online at www.mapinc.org/newsesdp/v98/a05.html. Also note Bruneau’s more recent comment that “in the vast majority of cases needle exchange programs drive HIV incidence lower.” The Washington Post February 27, 2005 : B06.

While there has clearly been an attempt to misuse the results of Bruneau’s research, the point we wish to underline here is that, in our view, there was a lack of equal collaboration and participation between the research team and front line workers in the needle exchange.

While CACTUS supports the relevance of qualitative research methods for furthering an understanding of IDUs, the authors of this paper objected to the relationship established between the researchers and the community based organization. One street outreach worker, for instance, stated that he felt he had no choice but to allow the researchers to accompany him during his outreach, since the research protocol had outlined this approach. He felt uneasy in doing so, however, since the presence of a researcher who did not know either the individual clients or the culture of the street in Montréal could damage his credibility amongst IDUs. This outreach worker was thinking through the long-term effects of ‘collaboration’ in the research study. Would participation ultimately impede relations of trust between him and the clients? In a similar vein, some staff members at the fixed site objected to the presence of a researcher who was disrespectful of how space was managed by the staff of the agency. Although the researcher was ostensibly in the fixed site only to observe, staff at the needle exchange cited several instances in which the individual initiated conversations with IDUs.

From the perspective of these authors, this approach did not respect the non-invasive nature of participant observation which the research team had assured the agency prior to beginning the study. From the perspective of research methods, this approach also raises a host of ethical and methodological problems, notably the difficulties in adequately observing a milieu when one is directly involved in it (Kirby et al., 2006). The CACTUS team made efforts to broach these issues with the researchers, and stated their clear objections to the presence of this individual in the fixed site. The individual remained on staff, however. CACTUS raised an important question in this regard; although the agency was a partner in the research, it had no say in the hiring or firing of the staff, despite the fact that these staff members were temporary guests in the work space of the agency.

Like the first example, this situation raises questions about the definition and nature of ‘collaboration’ between institutional researchers and community based organizations. Is ‘collaboration’ to be understood as merely offering a letter of support for the purposes of funding, with no further voice as to the way in which the research is conducted and its consequences for the staff and clients of the agency? This example also addresses the complicated issue of credibility with the clientele. As a community based organization, CACTUS must consider the extent to which the process of doing research impedes or facilitates contact and confidence with IDUs. Some members of CACTUS felt that these considerations were not reflected in the manner in which the research team conducted their study.

The third example builds on the previous two, and illustrates the efforts of CACTUS to learn from its previous history with community-based researchers. An outreach worker of the agency was approached by an institutional researcher. The researcher was interested in conducting a preliminary qualitative study on the relationship between street outreach and the prevention of HIV. It was the hypothesis of the study that it is necessary to create meaningful links with IDUs in and through street outreach, and that the work of HIV prevention can only be effective when this climate of confidence has been established. In principle, the outreach worker and other staff members of CACTUS recognized the tremendous impact and value of such a study; indeed, it could help justify funding street outreach through HIV/AIDS programs, without demanding an exclusively quantitative, statistical justification of the work carried out (i.e., the number of needles distributed in the course of street outreach).

There was an important procedural error on the part of the research team however; they approached the outreach worker directly, without contacting the Executive Director of the organization. Despite the fact that the outreach worker referred the researchers to the agency in order to obtain authorization for participation in the study, this official contact was not initiated by the researchers. When the outreach worker brought the matter to the team, there was general support for participation in the study. However, the team also decided that it was important to ensure that the interviewee and the CACTUS team would have an opportunity to validate the interpretation of the research results before their dissemination. This was a clear effort on the part of the agency to learn from its previous history with institutional researchers. The research team offered verbal assurance that validation of the results was possible. Based on such a guarantee, as well as a promise that it would be put in writing, the street outreach worker made an appointment to be interviewed by the research team.

The research team had not prepared a written agreement as to the validation of the research results when the designated time for the interview arrived, despite the fact that it was a clear condition of the participation of the agency in the project. With good will, the outreach worker granted the interview and referred the research team to the Executive Director of the agency. He reiterated that he was participating as a member of CACTUS, not as an individual, and that the research team therefore needed to enter into a formal written agreement with the agency. The outreach worker suggested that a delay of one week was appropriate for the preparation of these documents. One week later, CACTUS had not received the required documents. The outreach worker phoned the research team and requested that the documents arrive before the next team meeting, scheduled 10 working days after the date the interview had been granted. The worker was assured that these documents would be forthcoming by that date. The worker also clarified that if they were not received, CACTUS would make a decision about participating in the research project.

The documents were not sent by the time of the team meeting. CACTUS thus decided to withdraw from the research project until such time as a written agreement could be established. In discussions with the outreach worker, it was learned that the researchers had not signed a consent form with the interviewee, and that informed consent was not discussed orally at the beginning of the interview.

The agency sent two representatives to meet with the Department of Public Health research team representatives and to demand the cassette of the interview as well as any transcription documents which had taken place. Given the absence of any signed consent form or verbal consent, CACTUS and the outreach worker clarified that the researchers did not have authorization to use the data from the interview, nor any notes or reflections based on conversations with the outreach worker. CACTUS reiterated its motivation to participate in the research, but only if the organization could be assured of the right to refuse the results of the project.

The research team responded that it could not return the cassette to the agency due to confidentiality. They maintained that the interview was with an individual, not with the team of CACTUS. They did remit the cassette to the outreach worker, who accepted it with the clarification that he granted the interview as an official representative of CACTUS, and not as an individual. The research team also made the decision to not use the data collected from the outreach worker. The researchers expressed their regret that a good working relationship could not be established, and hoped that CACTUS could be involved in a larger research project on this subject matter. The research team was at that time preparing a grant application in this regard, to be submitted in the fall of 2000. CACTUS was not included as a partner agency in this grant application.

A VALIDATION AGREEMENT BETWEEN THE AGENCY AND INSTITUTIONAL RESEARCHERS: ENSURING THE PERSPECTIVE OF THE COMMUNITY IS REPRESENTED

The team of CACTUS responded to this situation by requesting a meeting with the research team and reiterating a motivation to participate. CACTUS had also prepared a 'Validation Agreement' to be signed between the agency and the researchers. As authors of this paper, we met on several occasions to write the text of this Validation Agreement. This was a pro-active move on the part of the organization, interested in clearly defining the terms of participation necessary for the agency to be involved in the research. The full text of the Validation Agreement is presented as an Appendix to this article.

The Validation Agreement contained several different elements as conditions for the organization's participation: clear, accessible language; length of the final report; timelines and delays for both the researchers and the agency to offer comments on the data; the agency's right of refusal of the results; and the responsibility of the researchers to represent the position of the agency, as well as the position of IDUs, in all public presentations of the research. CACTUS used the Validation Agreement as a way to negotiate clear definitions of roles and responsibilities for both the agency and the research team. It was designed to help learn from past experience with researchers. Several aspects of the Agreement illustrate this learning process.

The provisions around clear, accessible language were stipulated to ensure that the final report would be easily understood. Members of the agency had difficulty in the past reading reports with excessively technical language and academic jargon. The length of the final report was noted as a criterion because many front-line workers could not find the time to read a 100-page report in order to offer their comments. In this regard, the agency requested that any report exceeding 30 pages contain an Executive Summary. The section on timelines made clear provisions for appropriate delays amongst both the research team and the agency to offer their comments and provide feedback on preliminary drafts of the report. This section demanded recognition of the nature of community work, and sought to avoid a situation in which individuals would have to provide feedback on a report within a week or a few days in order to respond to the deadlines of institutional researchers. The agency's right of refusal of the research results was central to CACTUS and its participation. Importantly, the agency also stipulated that the research team needed to validate the findings with IDUs. Staff did not want to presume that their opinions represented those of IDUs. Furthermore, staff were interested in learning from the research process, if they held a different interpretation of the results than IDUs, that was an important lesson. Finally, the Validation Agreement outlined that the research team had to represent the perspective of the agency, as well as IDUs, in any and all public presentations of the research. This provision sought to avoid the type of situation CACTUS had previously experienced with a researcher who released the results with no consultation with the agency or its clients. If such an Agreement were in place in the context of the first situation described above, the researcher would have had to present the interpretation of the data to the agency and IDUs. The media reports on the subject would have been substantially different, and the agency and the Department of Public Health would not have been placed into a position of re-action subsequent to the press conference.

The research team refused to sign the Validation Agreement, with the justification that the timelines specified in the document would prevent them from completing their final report according to schedule. Although CACTUS offered to meet with them to negotiate the timelines in accord with their deadline, the offer was declined.

This refusal was significant, especially considering an invocation of 'timelines'. Since the agency had been involved in previous research projects, it was familiar with the fact that delays were often common in the preparation of a final report. More important, however, was the actual timing of the deadline. The communications between the researchers and the agency took place in the beginning of August 2000. The researchers wanted to complete their final report by the end of August. The authors of this paper believe that this 'deadline' was a function of grant applications to a large provincial granting institution (the grants being due in September). The research team had already been quite clear that they were planning to conduct a much larger study on this question, and that the current project was only a pilot investigation. In this regard, they had a marked interest in completing the final report for the pilot study in order to include it with their grant application. We feel that this criterion illustrates well how research was conducted first and foremost for the needs of the research team. The needs of a community-based agency and of the clients it serves could not be addressed in this framework. Full, equal participation in the interpretation and dissemination of the research results were sacrificed so that the researchers could apply for additional funds to embark on a larger project on the same theme.

CONCLUSION

As a community-based needle exchange, CACTUS is often approached by researchers to participate in various research projects. Numerous experiences with institutional researchers, however, have raised important questions about the implications of research, the definition of partnership between a community agency and institutional researchers, and the ownership of the data collected in a particular study.

These issues are at the forefront of the field of Community Based Research. It is generally recognized that CBR requires that organizations develop the capacities and skills needed to conduct a research project. As a preliminary first step, CACTUS developed a Validation Agreement to clarify the roles and obligations of both researchers and the community agency. This document outlines the conditions required for CACTUS to enter into an equal partnership with researchers.

The first time the agency proposed this Agreement to a research team, an understanding could not be reached between the agency and the researchers. Although no formal partnership was established, the authors of this paper do not view this in any way as a failure. On the contrary, in our view CACTUS sent a clear message to the researchers that partnership for the agency involves more than providing a letter of support for the purposes of funding agencies and unconditional access to the field. Equal participation means ensuring that the perspectives of the agency and its clients are represented in all public discussions of the research.

CACTUS has also been active in helping other community organizations learn from its experience. A workshop highlighting these examples was presented at the 2001 Canadian Skills Building Conference in Montréal (July 2001) to share the lessons learned at CACTUS. Similar agencies were encouraged to use the Validation Agreement as a model; they could modify it to suit their purposes, for instance, by demanding that the agency would have final say in the hiring and firing of research staff. The information presented here can also be useful for different Aboriginal communities and groups to think about how to negotiate the terms of partnership with institutional researchers. Readers especially interested in these issues may also be interested in examining some of the resources listed at the end of this article. They present some of the different agreements and principles of research necessary for a particular Aboriginal community to agree to work in collaboration with (outside) researchers.

The development of a Validation Agreement allowed CACTUS to be pro-active in its demand for inclusion in all aspects of the research process. This demand for inclusion -- for appropriate consultation throughout the research process and for ensuring that the interpretation of data included the perspective of the community agency and of IDUs -- was one of the most important lessons learned. In our view, a strategy which demands full consultation and involvement in the interpretation and dissemination of results is fundamental to the realization of Community Based Research.

SOME USEFUL RESOURCES RELATED TO NEGOTIATING PARTNERSHIP

AIATIS (The Australian Institute of Aboriginal and Torres Strait Islander Studies.) *Guidelines for Ethical Research in Indigenous Studies*. May 2000. Available online at www.aiatsis.gov.au

HCPO Policy and Research. *Protocol for Research, Publications and Recordings: motion, visual, sound, multimedia and other mechanical devices*. The Hopi Tribe. Available online at www.nau.edu/hcpo

Dene Cultural Institute. *Dene Cultural Institute Guidelines. (Guidelines for the conduct of participatory community research to document traditional ecological knowledge for the purpose of environmental assessment and environmental management.)* Available online at http://www.idrc.ca/en/ev-28709-201-1-DO_TOPIC.html

University of Victoria, Indigenous Governance. *Protocols and Principles for Conducting Research in an Indigenous Context*. Available online at http://web.uvic.ca/igov/programs/masters/igov_598/protocol.pdf .

REFERENCES

- Bruneau, J., Lamothe, F., Franco, E., Lachance, N., Désy, M., Soto, J., & Vincelette, J. (1997) High rates of HIV Infection among Injection Drug Users Participating in Needle Exchange Programs in Montréal: Results of a Cohort Study. *American Journal of Epidemiology*, 146.12 (Dec 15).
- Goyette, G., & Lessard-Hébert, M. (1987) *La Recherche-Action : ses fonctions, ses fondements, et son instrumentation*. Sillery, Québec: Presses de l'Université du Québec.
- Hankins, C., Gendron, S., & Tran, T. (1995) *CACTUS-Montréal : Profil comportemental de la clientèle et prévalence de l'infection par le VIH, 1^{er} octobre 1994 – 7 février 1995. Rapport numéro 6*. Montréal: Direction de la santé publique.
- Kirby, S., Greaves, L., & Reid, C. (2006) *Experience, Research, Social Change : Methods beyond the Mainstream. Second Edition*. Toronto: Garamond.
- Laconte, J., Killing Them Softly. Policy Review No. 90 (July-August 1998). Available online at www.policyreview.org/jul98/needles.html.
- Lamoureux, H., Mayer, R., & Panet-Raymond, J. (1984) *L'Intervention communautaire* Montréal: Éditions Saint-Martin.
- Lone Dog, L. (1999) 'Whose Genes Are They? The Human Genome Diversity Project.' *Journal of Health and Social Policy* 10.4 : 51–66.
- Smith, L.T. (1999) *Decolonizing Methodologies: Research and Indigenous Peoples*. London: Zed Books.
- Trussler, T., Marchand, R. (2000) Avec la collaboration de Yves Jalbert, Craig McClure, Darien Taylor. *Générer des connaissances pour l'action. Évaluation d'un atelier national sur la recherche communautaire*. Ottawa: Société canadienne du Sida.
- Zerda-Sarmiento, A., & Forero-Pineda, C. (2002) 'Intellectual property rights over ethnic communities' knowledge.' *International social science journal* 51.1 (171) : 99-114.

APPENDIX A – VALIDATION AGREEMENT

This agreement outlines the rights and obligations of CACTUS-Montréal and the research team for the project _____ with respect to the process for validating the results of the research project.

The team of researchers is comprised of _____

This agreement is drawn up to ensure that the perspective of CACTUS is represented in the final report of the project. It is also part of the development of an active collaboration between researchers and community based organizations.

To this end, following the data analysis, the researchers agree to present these results to CACTUS, in written form, in order to receive feedback from the agency. A draft of the final report is considered acceptable.

The researchers commit themselves to writing the final report and the preliminary results of the research in a language which is clear, accessible, and easily understood. Excessive jargon and verbosity is to be avoided, and *all* scientific terms and concepts introduced in the documents will be clearly explained.

In the case of a preliminary report exceeding 30 pages (excluding references), the researchers will provide a summary of the project and its results in a document not exceeding 20 pages (excluding references). In any case, the preliminary results will present all the elements of the project: its history, theoretical and methodological framework, the interpretation of the data, the action identified as required, as well as any proposed recommendations.

CACTUS agrees to provide its comments and feedback within a period of 15 working days following the reception of these preliminary results. The researchers may consider the absence of any formal response in this time period as an acceptance of the data analysis, except in the case of a written communication (letter, email or fax) to the research team requesting an extension of the time for an agency response. Any prolongation of the time is not to exceed 15 working days. Such a prolongation for the official response of the agency can only occur one time.

According to its abilities, CACTUS will offer its comments in written form. In the event that the members of CACTUS are more at ease in giving their comments in an oral format, the organization will communicate with the Principal Investigator to formalize such an arrangement. It is understood that the same delays and timelines apply, and that the organization needs to organize itself to offer all of its comments at one time. In this case, one person will provide all of the comments of CACTUS to the research team.

The response of CACTUS will identify the main points of the organization. These elements will be those most important for the agency. CACTUS may also identify additional elements which are less crucial but still pertinent. CACTUS will also provide its comments concerning the relevance of this research for its daily work.

The researchers agree to integrate the responses of CACTUS in the final report. All of the major elements of CACTUS's response will be included therein. The position of the agency as to the relevance of the research for its daily work will also be transmitted in the final report.

Following the incorporation of the comments of CACTUS, the researchers will present a draft of the final report to the agency. (This may be a second draft, if the research team previously presented a preliminary version of the research to the agency.) CACTUS will provide its comments concerning this version of the report within a period of 15 working days.

There may exist a gap between the position of the research team and that of CACTUS-Montréal with respect to the interpretation of the results. In this case, the gap will be noted in the final report, as well as justification of the

two positions (or several positions, in the event that this is the situation). If the response of the agency does not offer a justification for its position, the research team will solicit this essential information from the agency.

Aside from the positions of the research team and CACTUS, the researchers agree to validate the results with intravenous drug users. Any differences in the interpretation of the results with this group from either the research team or the agency CACTUS will be noted.

As to the interpretation of the results, when there exists a gap between the position of the researchers and that of the agency, or that of intravenous drug users, the researchers agree to represent this gap, as well as the reasons which underlie it, in any public diffusion of the research results (press conference, final report, executive summary, article, book, or other form of diffusion).

I, the undersigned, have read the agreement and agree to respect it. I am authorized to sign this agreement for my entire team.

Signature for the researchers

Signature for the agency

Date

Date

Canadian Journal of Aboriginal Community-Based HIV/AIDS Research (CJACBR)

Published by Canadian Aboriginal AIDS Network (CAAN)

Call for Papers

The Canadian Aboriginal AIDS Network (CAAN) is calling for papers to be considered for the second issue of the *Canadian Journal of Aboriginal Community-Based HIV/AIDS Research* (CJACBR). The CJACBR is a peer-reviewed journal, published by CAAN, which welcomes contributions from any author. Priority will be given to an author of Aboriginal ancestry/background, should manuscripts of comparable quality be available. First consideration will be given to innovative articles covering areas identified as HIV/AIDS research- which demonstrate the use of Aboriginal Community-Based Research (ACBR) methods or philosophy.

Articles should be submitted related to the following themes:

- **Aboriginal community-based HIV/AIDS research and development:** These are articles using either quantitative/qualitative research methods that are community-based in design and process and prepared in a language and manner appropriate to the audience.
- **Commentary:** These are opinion pieces. They speak to trends in communication or other issues of importance to professional communicators.
- **Dissemination of Results Findings:** These articles focus on results or recent findings related to Aboriginal Community Based HIV/AIDS Research.
- **Emerging Issues in Aboriginal Community-based HIV/AIDS Research (ACBR):** These articles focus on ground-breaking issues, findings and/or reports grounded in ACBR.
- **International work that includes an Aboriginal Canadian component:** Articles written for or by an international audience about Indigenous peoples, HIV/AIDS and/or related issues. Articles must include a Canadian component.
- **Ownership, Control, Access, and Possession:** Articles that focus on or enhance the use of the Ownership, Control, Access and Possession principle.
- **Professional/Personal Development:** These articles are based upon the author(s) particular expertise on a subject that will benefit service design/delivery and/or the career development of Aboriginal peoples involved in the HIV/AIDS movement.
- **Review:** These are critiques of new books, journal articles or anything else that would be appropriate for the audience of the CJACBR.
- **Stories:** These are personal accounts of experiences related to HIV/AIDS. Service providers can also submit an account of very successful and innovative approaches to address HIV/AIDS in Aboriginal communities.
- **Student work:** Students at the MA or PhD levels can submit articles (term papers, thesis, etc) that focus on HIV/AIDS in Aboriginal communities.

Submission Deadline: Monday, January 15, 2007. Manuscripts submitted via e-mail should be sent to Randy Jackson (randyj@caan.ca). All submissions are peer-reviewed (blind).

Inquiries: Information and policies for the Canadian Journal of Aboriginal Community-Based HIV/AIDS Research (CJACBR) are available at www.caan.ca. Inquiries related to the suitability of manuscripts, article submission, writing style guidelines, guidelines for Peer reviewers, updates or back issues, may be directed to Renee Masching (reneem@caan.ca) or Jann Ticknor (jannt@caan.ca).

