

Moving Mountains Conference

HIV-Specific Research in Northern Canada

Environmental Scan



Sarah Jackson and Jamie Reschny
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Defining North



The Public Health Agency of Canada's (PHAC) definition of north was utilized as the parameters of this environmental scan. PHAC defines north as “North of the southern limit of the discontinuous permafrost zone, with the addition of all of the Southern Yukon in the West; that section of Labrador south to and including Red Bay”.

Key Terms and Definitions

Acquired Immune Deficiency Syndrome (AIDS) - a disease of the immune system characterized by increased susceptibility to opportunistic infections

Community-based Research (CBR) - research that strives to be: Community situated -begins with a research topic of practical relevance to the community (as opposed to individual scholars) and is carried out in community settings.

Co-investigator (CI) - The on-site representative(s) of the Primary Investigator (PI) who conducts or directly supervises the conduct of the taking, importing, and exporting activities authorized under the permit.

Canadian Institutes of Health Research (CIHR) - the major federal agency responsible for funding health research in Canada.

Food Security - the state of having reliable access to a sufficient quantity of affordable, nutritious food

Greater Involvement of People Living With or Affected by HIV/AIDS (GIPA) - a principle that aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives (UNAIDS)

Highly Active Antiretroviral Therapy (HAART) - used to describe a combination of three or more anti-HIV drugs.

Human Immunodeficiency Virus (HIV) - a variable retrovirus that invades and inactivates helper T cells of the immune system and is a cause of AIDS and AIDS-related complex

Hepatitis C Virus (HCV)- a virus that causes Hepatitis C, an infectious disease affecting primarily the liver

Injecting Drug User (IDU)

The Ontario HIV Treatment Network (OHTN) - a collaborative network of researchers, health service providers, policy makers, community members and people with HIV who work together to promote excellence and innovation in HIV treatment, research, and education in Ontario.

Person Living with HIV/AIDS (PLHA)

Public Health Agency of Canada (PHAC) - an agency of the Government of Canada that is responsible for public health, emergency preparedness, and response and infectious and chronic disease control and prevention

Principal Investigator (PI) - the lead scientist or engineer for a particular well-defined science (or other research) project, such as a laboratory study or clinical trial.

Northern British Columbia

Project Title: The Prince George 2012 I-Track Survey

Research Team: Russ Callaghan (PI), Martha Risdale (Shoemaker),

Partners: PHAC, Northern Health Authority, Northern BC Aboriginal HIV/AIDS Coalition

Abstract: The Prince George 2012 I-Track Survey is part of the national I-Track surveillance system which is coordinated by the Public Health Agency of Canada (PHAC). I-Track is an ongoing surveillance system that monitors risk behaviours and HIV and hepatitis C infection among people who inject drugs (IDU) in Canada. The results of I-Track help all levels of government to assess existing interventions designed to help decrease the risk of HIV and hepatitis C infection among people who inject drugs.

Project Title: The Cedar project: prevalence and correlates of HIV infection among young Aboriginal people who use drugs in two Canadian cities

Research Team: Patricia M. Spittal (PI)

Partners: CIHR

Abstract: The Cedar Project is an observational study of Aboriginal youth living in Vancouver and Prince George, BC. Eligibility criteria include age (14-30 years) and self-reported use of non-injection or injection drugs at least once in the month before enrolment. Between October 2003 and April 2005, 512 participants were recruited and completed a questionnaire administered by an Aboriginal interviewer. Multivariable logistic regression analysis was used to model the independent association of demographic and behavioural variables of individuals with HIV infection.

Project Title: Exploring HIV and hepatitis C related vulnerability among young drug users in British Columbia: A multidisciplinary perspective

Research Team: Patricia M. Spittal (PI)

Partners: CIHR

Abstract: HIV infection is spreading among Canada's Aboriginal people. Although Aboriginal people make up only 4% of BC's population, they comprise more than 13% of all new HIV diagnoses in BC, and half of all babies infected with HIV in the province. One of the major ways in which HIV is spreading among Aboriginal people is by use of injection drugs such as cocaine and heroin. One recent study in Vancouver showed that Aboriginal people who injected drugs were getting HIV more than twice as fast as non-Aboriginal drug users. Aboriginal women seem to be at even higher risk. Moreover, Hepatitis C infection is spreading even more rapidly than HIV among Aboriginal people through the same route of transmission. This study will involve large numbers of young Aboriginal people (aged 14 to 30) who use drugs in Vancouver and Prince George. The study will use the scientific methods of both epidemiology and anthropology to understand the complex reasons underlying the increased vulnerability to HIV and Hepatitis C among young Aboriginal injection drug users. Only when we collectively understand why this happens, can urban, rural and reserve Aboriginal communities design and implement interventions that can stop and reverse these terrible epidemics.

Project Title: Impact of Food Security on Health Outcomes in People Living with HIV/AIDS Across Canada

Research Team: Robert Hogg (PI)

Partners: BCCFE

Abstract: This is a national study examining how access to safe and nutritious food influences the health of people living with HIV/AIDS. The project brings together stakeholders from AIDS Service Organizations, academics, and leaders in the field of service delivery, advocacy, HIV policy, and knowledge transfer and exchange in three provinces: British Columbia, Ontario, and Quebec.

Project Title: Opening Doors to Harm Reduction

Research Team: Heather Peters (PI)

Partners: CIHR

Abstract: Community-based research aims to build a greater depth of knowledge about hidden illicit drug use, service access and effective HIV prevention strategies in Northern and rural British Columbia

Project Title: Positive Living, Positive Homes

Research Team: Jennifer Evin Jones (PI), Cathy Worthington (PI)

Partners:

Abstract: Starting in 2014, the study will interview 125 people living with HIV at two time points as well as 60 service providers, service users and decision-makers from three communities in BC - Vancouver, Kamloops, and Prince George - each of which face different housing needs and pressures. Given the project's community-grounded research objectives, it is hoped and anticipated that this study will impact housing programs and policies in BC, promoting greater access to suitable, affordable and culturally appropriate housing services.

Project Title: The Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS)

Research Team: Mona Loutfy (PI), Alexandra de Pokemandy (PI), Robert Hogg (PI), Angela Kaida (PI)

Partners: CIHR, OHTN, CTN 262

Abstract: The Canadian HIV Women's Sexual and Reproductive Health Cohort Study, or CHIWOS, is a community-based research study that seeks to understand whether and how women-centred care may improve health outcomes for women living with HIV in Canada. CHIWOS is committed to the principles of GIPA (Greater Involvement of People Living with HIV/AIDS) and MIWA (Meaningful Involvement of Women Living with HIV/AIDS), and involves HIV-positive women in all stages of the research process, from conceptualization and study design, to survey development, to implementation and analysis. CHIWOS is guided by Critical Feminist and Social Justice frameworks and conducts analyses considering the impact of the Social Determinants of Health over the lifespan.

Project Title: "People need to listen to us": Empowering people living with HIV/AIDS through positive prevention

Research Team: Jiwon Slotwinski (Master Thesis)

Partners: UNBC

Abstract: This thesis research will explore the meanings and experiences of people living with HIV who participate in Positive Prevention (PP), a health promotion and harm reduction program designed help participants to engage in acquisition of useful knowledge to improve their own capacity to manage HIV-related illness and to adhere to treatment, as well as to enhance community capacity to provide psychosocial support. Participatory Action Research was undertaken in collaboration with research partners at Positive Living North, and AIDS Service Organization in Prince George, British

Columbia. The objective was to hear from people living with HIV and their support providers about how effectively PP meets their needs. Providing people with HIV a voice will improve our understanding of how ideas of preventive activities are actually received, and whether, and in what ways, quality of life has been improved.

In Canada the incidence rates of HIV in Aboriginal populations continue to grow. Reasons for the increased Aboriginal HIV incidence are varied including structural components such as socio-economic issues, and limited access to healthcare. The purpose of this study is to gain insight into how active injection drug use impacts adherence to antiretroviral treatment in Aboriginal people living in Prince George, British Columbia. Analysis revealed that healthcare providers need to be more *caring* and *consistent* in their approach. Adherence is facilitated by the knowledge of the health *consequences* of *non-adherence*; *trust* in healthcare providers; incorporating HAART into daily *routines*; receiving *support* from AIDS service organizations, and that combining HAART administration with *methadone* is an effective pathway to increase adherence. Finally the study found that the majority of participants expressed a feeling of disconnection from Aboriginal culture.

Project Title: HIV+ Aboriginal women speak of experience and strength in a Northern context

Research Team: Randene Wejr (Master Thesis)

Partners: UNBC

Abstract: Aboriginal women living with HIV in the north have a unique perspective regarding helpful and useful services as well as painful experience concerning gaps in services. This research examines the responses of eight Aboriginal women in this regard and, additionally, invites them to identify life factors, which have been particular sources of strength. Using an open interview method via snowball-sampling, the women were asked about services they found most helpful, resources that they thought were missing and to identify personal strengths contributing to their optimism and survival.

Project Title: Beyond the horizon: the greater involvement of people living with HIV/AIDS in western Canadian communities

Research Team: Christal Capostinsky (Masters Thesis)

Partners: UNBC

Abstract: Examines GIPA within the context of the definition of rural and north, and the social determinants of health that impact populations infected and affected by HIV/AIDS. Using focus groups, service providers in western Canadian communities were asked specific questions regarding the implementation of GIPA in their communities.

Project Title: The experience of active injection drug use on adherence to antiretroviral treatment in aboriginal people living in Prince George - a qualitative perspective

Research Team: Robert Sam Milligan (Masters Thesis)

Partners: Central Interior Native Health, UNBC

Abstract: In Canada the incidence rates of HIV in Aboriginal populations continue to grow. Reasons for the increased Aboriginal HIV incidence are varied including structural components such as socio-economic issues, and limited access to healthcare. The purpose of this study is to gain insight into how active injection drug use impacts adherence to antiretroviral treatment in Aboriginal people living in Prince George, British Columbia. Analysis revealed that healthcare providers need to be more *caring* and *consistent* in their approach. Adherence is facilitated by the knowledge of the health *consequences* of *non-adherence*; *trust* in healthcare providers; incorporating HAART into daily *routines*; receiving *support* from AIDS service organizations, and

that combining HAART administration with *methadone* is an effective pathway to increase adherence. Finally the study found that the majority of participants expressed a feeling of disconnection from Aboriginal culture.

Project Title: The Engage Study

Research Team: Dr. Robert Hogg (PI), Rosalind Baltzer Turje (CI), Jennifer Evin Jones (CI), Susann Richter (CI), Dr. Aranka Anema (CI), Dr. Angela Kaida, (CI), Dr. Lawrence McCandless (CI), Dr. Julio SG Montaner (CI), Dr. David Moore (CI), Dr. Denis Nash (CI), Surita Parashar

Partners: CIHR, BCCFE

Abstract: The Engage Study aims to find out more about people's decisions and attitudes toward beginning highly active antiretroviral therapy (HAART). It is a project funded by the Canadian Institutes of Health Research (CIHR) and is led by the BC Centre for Excellence in HIV/AIDS with the help of many collaborators and co-investigators. Participation in the study involves filling out a baseline survey and another follow-up survey 6 to 12 months later. The surveys will assess the treatment attitudes, behaviours and beliefs of HIV-positive individuals who are newly starting treatment in BC.

Project Title: HIV specific drug-drug interaction

Research Team: Dr. Arun Verma (PI), Jennifer Hawkes (CI), Denise Kreutzweiser (CI), Alesha Cvenkel (CI)

Partners: Northern Health

Abstract: A retrospective study analyzing various drug-drug interaction trends among marginalized, HIV positive patients living in Northern BC.

Project Title: Stable Homes, Strong Families: Housing and Health for Aboriginal Peoples Living with HIV and AIDS

Research Team: Saara Greene (PI), Charlie W. Hill (PI), Renee Masching (PI),

Partners: CIHR

Abstract: This study aims to identify and work towards addressing gaps in appropriate housing options that support cultural identity and concepts of home for Aboriginal peoples living with and affected by HIV and AIDS. A multiple method approach involving a programmatic and policy scan and digital story-telling will be used by our academic and community-based research collaborative to work with Aboriginal people living with and affected by HIV and AIDS to explore cultural meanings of housing and home and how this links with health status and HIV transmission. This will be used within an integrated approach to knowledge translation and exchange to support a culturally appropriate response to Aboriginal housing needs in the context of HIV. Our community-based research design is consistent with Indigenous scholarship, the principles of Ownership, Control, Access and Possession, and the Federal Initiative to Address HIV/AIDS in Canada.

Project Title: Incentives

Research Team: Dr. Mark Hull (PI), Dr. Julio Montaner (PI), Dr. Rolando Barrios, Dr. Richard Harrigan (CI), Dr. Marianne Harris (CI), Dr. Robert Hogg (CI), Dr. Thomas Kerr (CI), Dr. Viviane Dias Lima (CI), Dr. David Moore (CI), Dr. Kate Shannon (CI), Dr. Evan Wood (CI), Dr. Reka Gustafson

Partners: US National Institute on Drug Abuse

Abstract: The study aims to find new and effective means of improving antiretroviral uptake and adherence in hard-to-reach populations. This may benefit the health of individuals, as well as public health and society, by preventing new HIV infections. This randomized trial will measure the

effectiveness of providing contingent reinforcers as a strategy for increasing adherence to HIV medications in order to achieve long-term, sustained virologic suppression.

Project Title: Evaluation of Post-HIV Exposure Prophylaxis at UHNBC

Research Team: Catherine Cheung (PI), Amy Sauerwein (PI), Alicia Ridgewell (PI), Aleisha Thornhill (PI), Dr. Abuobeida Hamour (PI), Linda Akagi (PI), Dana Cole (PI)

Partners: Pharmacy Resident Program UHNBC

Abstract: A retrospective chart review evaluating current adherence to guidelines, and an assessment of the effect of post-HIV exposure education by a pharmacy resident on UHNBC staff.

Project Title: A collaborative approach to understanding and improving Aboriginal people's access to HIV services in Northern BC

Research Team: Lesley A. Cerney (PI), Dara H. Culhane (CI)

Partners: CIHR

Abstract: Overall declines in Canadian rates of HIV infection mask dramatic increases among vulnerable populations, such as Aboriginal women, youth, and intravenous (IV) drug users. Scholars attribute the additional burden of illness among Aboriginal people to the legacy of colonialism and history of social marginalization. In a recent study Aboriginal women reported experiencing encounters with health providers as invalidating, which discouraged them from seeking health services. While colonialism continues to shape relationships between health providers and Aboriginal patients, we know little about how this legacy affects the delivery of HIV services. Specifically, how are differences in power experienced and negotiated in patient-provider relationships; how do Aboriginal people with HIV and their health providers experience the delivery of these services; and how can an understanding of Aboriginal people's experiences contribute to improvements in HIV policies and practices? This study uses ethnographic methods of participant observation, interviews and focus groups to examine these questions in the relationships between health providers and Aboriginal people with HIV. Patient-provider relationships will be observed during provision of HIV services. Parties will also be interviewed separately with attention to the experiences of Aboriginal women, youth and IV drug users. Participants will be engaged in discussing factors identified as barriers in accessing HIV services - to increase understanding between patients and providers. Development of a collaborative methodology will extend conventional approaches to participatory research by involving parties in analysis of data and in knowledge translation activities. Building on lived experiences of those most at risk for HIV, and those providing HIV services, this research will identify innovative new strategies for improving HIV policy and practice and for increasing access to HIV prevention, treatment and support services.

Table 1 Northern BC Project Summary Characteristics

	Year	Common Title	Population Studied	Type of Study	Project Funder
1	2012	I-Track Survey	IDUs	HIV and HCV Prevalence	PHAC, NHA, and NBCFN HIV/AIDS Coalition
2	2003- Ongoing	Cedar Project	Young Aboriginal People (14-30) who use injection and non-injection drugs in Vancouver and Prince George	Community-based prospective cohort study	CIHR
3	2005-2010	Exploring HIV and hepatitis C related vulnerability	Young Aboriginal People (14-30) who use injection and non-injection drugs in Vancouver and Prince George	Increased vulnerability to HIV and Hepatitis C among young Aboriginal injection drug users	CIHR
4	1998 - 2011	Food Security	HIV-positive IDUs	Association between food security and mortality	BCCFE
5	Ongoing	Opening Doors to Harm Reduction	Residents of Quesnel	Hidden illicit drug use, service access and effective HIV prevention strategies	CIHR
6	Ongoing	Positive Living, Positive Homes		Housing and HIV/AIDS in British Columbia	
7	Ongoing	CHIWOS	HIV Positive women living in Ontario, Quebec, and British Columbia	Experiences of HIV Positive Women	CIHR, OHTN, CTN 262
8	2011	People need to listen to us	People living with HIV who participate in Positive Prevention	Experiences of people living with HIV who participate in Positive Prevention	
9	2011	HIV+ Aboriginal women speak of experience and strength in a Northern context	Aboriginal Women living with HIV in the north	Interviews with eight Aboriginal women living with HIV in the north	
10	2013	Beyond the horizon	Service providers in western Canadian communities.	Focus groups regarding the implementation of GIPA in their communities	
11	2011	The experience of active injection drug use on adherence to	Aboriginal people living with HIV, involved in active injection drug	Eight interviews conducted and analyzed using a grounded theory methodology. Aims to gain	

		antiretroviral treatment in aboriginal people living in Prince George	use in Prince George	insight into how active injection drug use impacts adherence to antiretroviral treatment in Prince George.	
12	Ongoing	The Engage Study	HIV-positive individuals who are newly starting treatment in BC.	Aims to find out more about people's decisions and attitudes toward beginning highly active antiretroviral therapy (HAART)	CIHR
13	Ongoing	HIV specific drug-drug interaction	Patients who were receiving anti-retroviral therapy through CINHS from Sept 1, 2011 to June 30, 2013	Drug-drug interaction trends among marginalized, HIV positive patients living in Northern BC	Northern Health
14	Ongoing	Stable Homes, Strong Families	Aboriginal People living with HIV/AIDS	Cultural meanings of housing and home and how this links with health status and HIV transmission	CIHR
15	Ongoing	Incentives	People living with HIV	Contingent reinforcement in the engagement and retention of Drug Users in HAART programs	US National Institute on Drug Abuse
16		Evaluation of Post-HIV Exposure Prophylaxis at UHNBC		Current adherence to guidelines, and an assessment of the effect of post-HIV exposure education	Pharmacy Residency Project
17	2007-2012	A collaborative approach to understanding and improving Aboriginal people's access to HIV services in Northern BC	Health providers, Aboriginal women, youth and IV drug users	Relationships between health providers and Aboriginal people with HIV	CIHR

Northern Alberta

Project Title: Exploring Increased HIV Program Delivery in Northern Alberta

Research Team: Brenda Yamkowsky (Master Thesis)

Partners:

Abstract: As a community-based AIDS service organization, HIV North Society plays a key role in providing programming and supports for persons at risk or living with HIV in a vast, primarily rural region of Northern Alberta. This thesis examines the question: How can HIV North Society use collaborative strategies to increase and sustain the delivery of programming within Northern Alberta? The action research was performed utilizing a mixed-methods approach, which included an online survey and conversation café. The research results suggest that there is potentially much value in new collaborative actions to increase program delivery.

Project Title: Prevalence and correlates of HIV and hepatitis B virus coinfection in Northern Alberta

Research Team: C Pittman (PI), S Plitt (PI), T Birse (CI), K Doucette (CI), B Romanowski (CI), R Cooper (CI), S Houston (CI), AE Singh (CI)

Partners: David and Beatrice Reidford Research Scholarship

Abstract: The present study was a retrospective database review of all HIV-infected (HIV+) individuals in Northern Alberta from 1982 to 2010 and a chart review of HBV surface antigen-positive individuals for whom charts were available (46.2%). The prevalence of coinfection with HBV in HIV-infected patients in Northern Alberta is lower than reported in other developed nations. The pattern of coinfections in Northern Alberta likely follows immigration trends. Recognition and management may be improving with time; however, further research and additional strategies are required to enhance the prevention, identification and management of HBV infection in HIV-infected individuals.

Project Title: All-cause and HIV-related Mortality Rates Among HIV-infected Patients After Initiating Highly Active Antiretroviral Therapy: The Impact of Aboriginal Ethnicity and Injection Drug Use

Research Team: Leah J. Martin, PhD (PI), Stan Houston, MD (CI), Yutaka Yasui, PhD (CI), T. Cameron Wild, PhD (CI), L. Duncan Saunders, MBBCh, PhD (CI)

Partners: University of Alberta

Abstract: Aboriginals are over-represented in Canada's HIV epidemic and are commonly infected with HIV via injection drug use (IDU); however, little is known about the impact of Aboriginal ethnicity on mortality after starting highly active antiretroviral therapy (HAART). Therefore, we compared mortality rates between Aboriginal and non-Aboriginal HIV patients and between IDU and non-IDU HIV patients after they initiated HAART. Compared to non-Aboriginals, Aboriginal HIV patients suffer higher all-cause and HIV-related mortality rates after starting HAART. The strongest and most significant predictor of higher all-cause mortality was IDU. Future research should examine reasons for the observed poorer survival of Aboriginal and IDU HIV patients after initiating HAART to develop interventions to improve the prognosis for these vulnerable populations.

Project Title: Spider Weaving: STI/HIV Prevention Using Popular Theatre and Action Research in an Indigenous Community

Research Team: Josephine Auger (PhD Thesis)

Partners: University of Alberta

Abstract: A participatory action research study was conducted in Alberta, Canada to examine the experiences of HIV-positive Aboriginal individuals in the period following diagnosis. The goals of the study were to identify factors that limited or enhanced risky behaviours, and to develop and implement an intervention to promote healthier lifestyles for Aboriginal persons living with HIV/AIDS (APHAs). Thirty-one Aboriginal men and women participated in the study. Receiving and adapting to a positive HIV diagnosis was a difficult process for most participants, and resulted in a number of potentially harmful behaviours and painful emotions. Gradually, most participants accepted the diagnosis and found ways to take better care of themselves. Nevertheless, they faced ongoing challenges, including stigma and discrimination, coping with histories of abuse, and confidentiality concerns. The intervention included the development and presentation of a skills-building workshop for individuals living with HIV, some of whom were study participants. In addition, members of the team visited several communities in Alberta to discuss the findings and the most appropriate strategies to assist individuals living with HIV to adopt healthier lifestyles.

Project Title: The patterns of use and outcomes of highly active anti-retroviral therapy (HAART) among AIDS patients treated by the northern Alberta HIV program

Research Team: Leah J. Martin, University of Alberta (PI), Leslie D. Saunders (CI), Stan C. Houston (CI)

Partners: CIHR

Abstract: The recent introduction and use of an HIV/AIDS drug therapy combination, called HAART, has resulted in reduced AIDS-related morbidity and mortality [Hogg et al. CMAJ 1999; 160: 659-65]. However, we know little about the effectiveness of HAART among inner-city AIDS patients in North America. In Northern Alberta, all persons diagnosed HIV+ are referred to the Northern Alberta HIV Program (NAHIVP) for treatment; most of these patients are inner-city residents who deal with numerous social issues in addition to their illness. The purpose of our research is to learn more about the combinations of HAART drugs that NAHIVP patients are prescribed, and to evaluate the effectiveness of their therapies, especially in terms of patient quality of life. Improving our understanding about which HAART drug combinations are associated with the most successful outcomes will help physicians to prescribe more effective treatments. We expect that more effective treatments will improve the quality of life for the vulnerable AIDS population in Northern Alberta.

Table 2 Northern Alberta Project Summary Characteristics

	Year	Source	Population Studied	Type of Study	Project Funder
1	2013	Exploring Increased HIV Program Delivery in Northern Alberta	Funders, Board Members, Community Members, and Persons Living with HIV	Collaborative strategies that can be utilized by HIV North Society	
2	2014	Prevalence and correlates of HIV and hepatitis B virus coinfection in Northern Alberta	2844 HIV positive patients	Rates of HBV correlation among all HIV-infected (HIV+) individuals in Northern Alberta from 1982 to 2010	David and Beatrice Reidford Research Scholarship
3	2011	All-cause and HIV-related Mortality Rates Among HIV-infected Patients After Initiating Highly Active Antiretroviral Therapy	548 HIV Positive Patients	Mortality rates among HIV-infected patients after initiating HAART	
4	2010	Spider Weaving	HIV Positive Aboriginal Individuals	Experiences of HIV-positive Aboriginal individuals in the period following diagnosis	
5	2005-2008	The patterns of use and outcomes of highly active anti-retroviral therapy (HAART)	Northern Alberta HIV Program (NAHIVP) patients	Effectiveness of the HAART therapies prescribed to NAHIVP patients	CIHR

Northern Saskatchewan

Project Title: Northern Saskatchewan HIV/AIDS and hepatitis C awareness initiative

Research Team: Silvia Abonyi (PI)

Partners: CIHR

Abstract: The major objective of this research project, conducted between October 2002 and June 2005, was to collect baseline information on northern peoples' perceptions and experiences of HIV/AIDS, as well as to identify local and regional capacities and gaps for preventing and managing HIV/AIDS. Because hepatitis C comes to communities in many of the same ways as HIV and AIDS, it was also included in the research.

Project Title: Determining Factors Toward Improving HIV/AIDS Support Structures in Northern Saskatchewan Aboriginal Communities

Research Team: Silvia Abonyi (PI)

Partners: CIHR

Abstract:

Table 3 Northern Saskatchewan Project Summary Characteristics

	Year	Source	Population Studied	Type of Study	Project Funder
1	2006	Northern Saskatchewan HIV/AIDS and hepatitis C awareness initiative	People living in Northern Saskatchewan	Northern peoples' perceptions and experiences of HIV/AIDS. Identifying local and regional capacities and gaps for preventing and managing HIV/AIDS	CIHR
2	Ongoing	Determining Factors Toward Improving HIV/AIDS Support Structures in Northern Saskatchewan Aboriginal Communities			CIHR

Northern Manitoba

Project Title: Improving infectious disease treatment outcomes among vulnerable populations

Research Team: Dr. M. Becker (PI)

Partners: Manitoba Health Research Council

Abstract: Improving infectious disease treatment outcomes among vulnerable populations. The aim of the project is to improve HIV treatment outcomes among vulnerable populations in Manitoba specifically, in Canada, and more broadly in low and middle-income countries such as India. Several aspects critical to prevention and care will be investigated including: 1. Barriers to testing and accessing treatment 2. Monitoring treatment 3. Adherence and risk factors for failure 4. Delivery of prevention and care

Project Title: Missed Opportunities for Diagnosis of HIV Epidemiological Study

Research Team: Dr. M. Becker (PI)

Partners: Department of Internal Medicine/ University Medical Group

Abstract: The mandate of the Manitoba HIV program is to provide high quality comprehensive care and knowledge gained from this study will be important for evidence based programming. The specific objectives of this study are to: 1. Describe the patterns and determinants of health care utilization among newly diagnosed HIV positive persons in Manitoba from 2007-2010, comparing and contrasting those presenting late in their disease course with those presenting earlier. 2. Identify missed opportunities for earlier diagnosis of HIV in persons presenting for health care. 3. Understand sexual networks and substance using behaviors of newly diagnosed HIV positive persons from 2009 and 2010 attending the Manitoba HIV Program Clinics

Table 4 Northern Manitoba Project Summary Characteristics

	Year	Source	Population Studied	Type of Study	Project Funder
1	2009-2012	Improving infectious disease treatment outcomes among vulnerable populations	Vulnerable populations	Infectious disease treatment outcomes among vulnerable populations.	Manitoba Health Research Council
2	2010-2011	Missed Opportunities for Diagnosis of HIV Epidemiological Study	Newly diagnosed HIV Positive Persons	Patterns and determinants of health care utilization among newly diagnosed HIV positive persons in Manitoba from 2007-2010.	Department of Internal Medicine/University Medical Group

Northern Ontario

Project Title: Promising HIV Prevention Programs and Interventions for Rural and Remote Regions in Canada: Services Scoping

Research Team: Catherine Anne Worthington (PI)

Partners: CIHR

Abstract: The aim of this services scoping study is to a) collect program information on promising HIV prevention programs for rural and remote regions in Canada from selected AIDS Service Organizations (ASOs), other community based organizations (CBOs), and clinics providing HIV prevention programs/interventions in rural/remote areas of Canada, b) develop and share an electronic compendium based on this information, and c) develop a research proposal on promising HIV prevention programs. Study outputs will include the electronic compendium, a journal article manuscript and a CIHR funding application.

Project Title: Impact of Food Security on Health Outcomes in People Living with HIV/AIDS Across Canada

Research Team: Robert Hogg (PI)

Partners: BCCFE

Abstract: This is a national study examining how access to safe and nutritious food influences the health of people living with HIV/AIDS. The project brings together stakeholders from AIDS Service Organizations, academics, and leaders in the field of service delivery, advocacy, HIV policy, and knowledge transfer and exchange in three provinces: British Columbia, Ontario, and Quebec.

Project Title: Advancing HIV services research: Expanding Andersen's health service utilization framework

Research Team: Catherine Anne Worthington (PI)

Partners: CIHR

Abstract: HIV services research and evaluation have shown that in order to be effective, HIV services need to be tailored to the specific contexts, cultures and locales of populations infected with, and at risk for, infection to HIV through collaborative research endeavours, particularly since many of these populations are vulnerable or marginalized. The goal of this five-year program of research, supported by a CIHR New Investigator award, is to conduct a series of collaborative and interdisciplinary research projects to improve HIV health services for specific groups. Two projects focus on services for those living with HIV, and two projects focus on services for vulnerable populations. The first project (funded by CIHR for 2003-2005) will provide rehabilitation and HIV professionals with information on the ways in which rehabilitation services could improve health care for those living with HIV. The second project (funded by SSHRC for 2003-2006) will provide HIV clinicians with information on ways to improve clinical research practices for HIV patients. The third research project (submitted to CIHR) will provide information to Aboriginal and HIV service providers on the knowledge, attitudes, experiences, and beliefs of Ontario Aboriginal women about HIV and HIV risks to assist in services development for this vulnerable population. The fourth research project (to be prioritized for funding by Health Canada for 2004) will provide a team of HIV and street youth agencies with information on the spectrum of street youth in Calgary, their HIV and health risks, strengths, coping mechanisms, and service needs. All of these projects are collaborative in nature with direct participation of service providers and/or members of the populations under study to ensure knowledge exchange and timely uptake of research results.

Project Title: Capacity building: Culturally sensitive training for staff and volunteers of First Nations' community organizations providing HIV/AIDS services

Research Team: Basanti Bhaduri Majumdar (PI), Gina M. Brown (CI), Amiram Gafni (CI), Tracey L. Chambers, McMaster University; (CI), Jacqueline Gail, McMaster University (CI)

Partners: CIHR

Abstract: Culturally sensitive education improves knowledge and awareness of HIV/AIDS, and decreases infection rates, stigma and fear within communities. Education of this nature, while making inroads in much of North America, often fails to recognize the specific needs of North American Aboriginals, who represent a rapidly growing proportion of HIV-positive tests. In Canada, many organizations exist to support Aboriginal people coping with HIV/AIDS; however, they lack resources to adequately care for clients who often live in remote areas. Staff and volunteers of such organizations can often feel unsupported and overwhelmed by their work. This project aims to train a group of staff and volunteers to strengthen these organizations. Working in collaboration, McMaster University, Union of Ontario Indians, 2-Spirited People of the First Nations, the Association of Iroquois and Allied Indians, Grand Council Treaty #3 and the Nishnawbe Aski Nation will combine resources to conduct a project examining the development, implementation and evaluation of a culturally sensitive training program in HIV/AIDS for staff and volunteers of their respective organizations. Each group will contribute staff and volunteers to form a core group of trainees who will be trained in culturally sensitive HIV/AIDS prevention and education; the core group will then separate and each member will train others within their respective organizations. Findings from this project will be used to create a resource package that will provide education and training to future staff and volunteers of these organizations, enabling them to maintain a network of educators and trainers and build their capacity through mass education. Furthermore, this project can become a model for AIDS organizations in other provinces, demonstrating how to develop and use existing resources to increase awareness and reduce the spread of HIV/AIDS.

Table 5 Northern Ontario Project Summary Characteristics

	Year	Source	Population Studied	Type of Study	Project Funder
1	Ongoing 2013-	Promising HIV Prevention Programs and Interventions for Rural and Remote Regions in Canada	Prevention programs/interventions in rural/remote areas of Canada	Services scoping study	CIHR
2	1998 -2011	Food Security	HIV-positive IDUs	Association between food security and mortality	BCCFE
3	2005-2010	Advancing HIV services research	Service providers and/or members of vulnerable populations	Improving HIV health services for specific groups	CIHR
4	2005-2006	Capacity building	Staff and volunteers in organizations supporting Aboriginal people living with HIV/AIDS	Development, implementation and evaluation of a culturally sensitive training program in HIV/AIDS	CIHR

Northern Quebec

Project Title: Impact of Food Security on Health Outcomes in People Living with HIV/AIDS Across Canada

Research Team: Robert Hogg (PI)

Partners: BCCFE

Abstract: This is a national study examining how access to safe and nutritious food influences the health of people living with HIV/AIDS. The project brings together stakeholders from AIDS Service Organizations, academics, and leaders in the field of service delivery, advocacy, HIV policy, and knowledge transfer and exchange in three provinces: British Columbia, Ontario, and Quebec.

Project Title: Analysis of the implementation of Chiyikiyaa, a program to prevent HIV infection and promote sexual health among students in two communities in the Terres-Cries-de-la-Baie-James region (Eeyou Istchee)

Research Team: Manon Dugas (PI), Joanne Otis (PI), Marlene Beaulieu (CI), Francoise Caron (CI), Gaston Godin (CI), Joseph Levy (CI)

Partners: CIHR

Abstract: [translated from the original French] Adolescents in Aboriginal communities are at high risk of contracting HIV and other sexually transmitted infections (STIs) (Statistics Canada, 2005; Calzavara et al., 1998). A peer training program known as Chiyikiyaa will be tested in two Terres-Cries-de-la-Baie-James communities (Waskaganish and Waswanipi). Under the supervision of a teacher, students in secondary IV will be asked to develop creative and educational activities around five themes. Later, these activities will be shared with younger students (secondary I and II). The themes are as follows: delaying sexual relations; communication; being sexually responsible; developing egalitarian relationships; and condom use. The proposed study will pursue the following objectives: 1. describe the degree to which the program has been implemented and the factors that have facilitated or obstructed implementation; 2. evaluate the process and structure of the program, as well as the achievement of its objectives; 3. develop measurement instruments to evaluate program effects; 4. lay the groundwork to transfer the program to other communities. A variety of qualitative and quantitative methodologies will be employed to analyse the implementation process over a three-year period. This study will make it possible to offer a relevant and culturally appropriate program in the longer term to adolescents in Terres-Cries-de-la-Baie-James. The project itself will contribute to efforts being made in Canada to prevent new cases of HIV infection, as well as the transmission of HIV among Aboriginal youth.

Project Title: Experience of motherhood and antiretroviral treatment among Aboriginal, Haitian, African and Quebec women living with HIV/AIDS

Research Team: : Isabelle Toupin, Université du Québec à Montréal (UQAM) (PI), Joanne Otis (CI), Mylène Fernet (CI),

Partners: CIHR

Abstract: In Canada, and particularly in Quebec, so far, there have been few studies on representations of antiretroviral therapies for HIV and their impact on the daily lives of women living with HIV. There have been even fewer studies on African, Haitian and Aboriginal women in a migration environment (Gallant, 2000; Lévy et al., 2000; Rogers et al., 2000; Sendi et al., 1999). Little consideration has been given to the experience of motherhood, which appears to be central in establishing a relationship to living with HIV, adhering to treatment and ensuring secondary prevention. There are few studies on understanding the experiences of women living with HIV/AIDS and receiving antiretroviral treatment, especially how they

relate to their children (desire for children, pregnancy, childbirth, motherhood, mother-to-child transmission). This study will contribute to the advancement of knowledge, which is currently limited. Once the study is completed, we can identify strategies for secondary prevention of HIV/AIDS. We can also better understand the issues involved in adhering to antiretroviral treatment in the ethnic and cultural milieus targeted by the project.

Project Title: Strengthening community-based approaches to HIV/AIDS education, screening, and treatment among Canadian Inuit youth

Research Team: Jeanette Doucet (PI), Jacqueline C Gahagan (PI), Aideen Frances Reynolds (PI), Audrey Steenbeek (PI), Chris Patrick Archibald (CI), Pitsulala Sarah Lyta (CI)

Partners: CIHR

Abstract: This project will begin to explore the complex interplay between culture, youth health, and gender empowerment regarding HIV/AIDS risk within Inuit communities, and determine research priorities for a multi-year study. There is an urgent need for a clearer picture of the dynamics and epidemiology of HIV risk among Inuit in Canada. Current Inuit HIV data tends to get lost among Aboriginal or broader Canadian statistics and under-represents the true situation for Inuit in Canada. This research seeks to contribute to this understanding and hopes to guide the development of sustainable community based participatory options for HIV/AIDS interventions that are sensitive to the challenges of health promotion and health care provision in Northern communities. The project employs a community-based research methodology involving direct participation from Inuit organizations and community members. Moreover, on account of the barriers related to testing in small remote communities (lack of anonymity, stigma and discrimination, lack of access to care upon receipt of a positive test, lack of AIDS Service Organizations in the North), this community-based research methodology provides an important opportunity to build capacity for health care providers and to improve access to education, testing (anonymous testing with pre- and post-test counselling), diagnosis, care, treatment and support.

Table 6 Northern Quebec Project Summary Characteristics

	Year	Source	Population Studied	Type of Study	Project Funder
1	1998 - 2011	Food Security	HIV-positive IDUs	Association between food security and mortality	BCCFE
2	2006-2009	Analysis of the implementation of Chiyyikiyaa	Youth in two Aboriginal communities	Programs to prevent HIV infection among Aboriginal youth	CIHR
3	2006-2009	Experience of motherhood and antiretroviral treatment	Aboriginal, Haitian, African and Quebec women living with HIV/AIDS	Motherhood and antiretroviral treatment	CIHR
4	2007-2008	Strengthening community-based approaches to HIV/AIDS education, screening, and treatment among Canadian Inuit youth	Inuit Communities in Nunavut and Quebec	Interplay between culture, youth health, and gender empowerment regarding HIV/AIDS risk within Inuit communities	CIHR

Labrador

Project Title: Aboriginal community-based research capacity-building initiative Canada: An initiative for Eastern Canada and Nunavut

Research Team: Randy Jackson (PI), J.K. Barlow (PI),

Partners: CIHR, Canadian Aboriginal AIDS Network (CAAN)

Abstract: Under an existing CBR capacity-building project (now entering its sixth year of operation), CAAN Aboriginal Research Technical Assistant Program is part of a continuing strategic approach to address rates of HIV/AIDS infection and research capacity building needs in Aboriginal communities. Research technical assistants will address the original goals under this current initiative: 1. To provide support for the development of research skills within Aboriginal communities; 2. To promote cultural competence in research among professional and academic researchers undertaking work in collaboration with Aboriginal communities; and 3. To assist in the design of HIV/AIDS research that is both methodologically sound, culturally competent, respectful, and relevant. Specific objectives include: a) Explore the development of both e-learning and virtual training opportunities in partnership with an appropriate academic institution (e.g., department and/or ACADREs) and another non-governmental organization (e.g., Ontario HIV Treatment Network and/or the Wellesley Institute or the Community-Based Research Centre) with a vision to implement an Aboriginal CBR certification process; b) Build on our success with an Aboriginal-specific CBR journal focusing on continued dissemination activities, including publications and conference presentations; c) Continue the implementation of CBR mentorship thereby providing support for the development of research skills; d) Explore the feasibility of partnership activities in support of expanded CBR capacity-building to benefit the respective mandates of both CBRFs and Aboriginal RTAs; e) Develop and offer a workshop focusing on Aboriginal research ethics; f) Participate in a CAAN sponsored development grant focused on housing issues; and g) the RTA will work closely with members of our National Research Advisory Committee as each of the above activities are developed and delivered.

Table 7 Labrador Project Summary Characteristics

	Year	Source	Population Studied	Type of Study	Project Funder
1	2007-2009	Aboriginal community-based research capacity-building initiative Canada	Aboriginal communities in Eastern Canada and Nunavut	CBR capacity-building project	CIHR

Nunavut

Project Title: Aboriginal community-based research capacity-building initiative Canada: An initiative for Eastern Canada and Nunavut

Research Team: Randy Jackson (PI), J.K. Barlow (PI), Canadian Aboriginal AIDS Network (CAAN)

Partners: CIHR

Abstract: Under an existing CBR capacity-building project (now entering its sixth year of operation), CAAN Aboriginal Research Technical Assistant Program is part of a continuing strategic approach to address rates of HIV/AIDS infection and research capacity building needs in Aboriginal communities. Research technical assistants will address the original goals under this current initiative: 1. To provide support for the development of research skills within Aboriginal communities; 2. To promote cultural competence in research among professional and academic researchers undertaking work in collaboration with Aboriginal communities; and 3. To assist in the design of HIV/AIDS research that is both methodologically sound, culturally competent, respectful, and relevant. Specific objectives include: a) Explore the development of both e-learning and virtual training opportunities in partnership with an appropriate academic institution (e.g., department and/or ACADREs) and another non-governmental organization (e.g., Ontario HIV Treatment Network and/or the Wellesley Institute or the Community-Based Research Centre) with a vision to implement an Aboriginal CBR certification process; b) Build on our success with an Aboriginal-specific CBR journal focusing on continued dissemination activities, including publications and conference presentations; c) Continue the implementation of CBR mentorship thereby providing support for the development of research skills; d) Explore the feasibility of partnership activities in support of expanded CBR capacity-building to benefit the respective mandates of both CBRFs and Aboriginal RTAs; e) Develop and offer a workshop focusing on Aboriginal research ethics; f) Participate in a CAAN sponsored development grant focused on housing issues; and g) the RTA will work closely with members of our National Research Advisory Committee as each of the above activities are developed and delivered.

Project Title: Strengthening community-based approaches to HIV/AIDS education, screening, and treatment among Canadian Inuit youth

Research Team: Jeanette Doucet (PI), Jacqueline C Gahagan (PI), Aideen Frances Reynolds (PI), Audrey Steenbeek (PI), Chris Patrick Archibald (CI), Pitsulala Sarah Lyta (CI)

Partners: CIHR

Abstract: This project will begin to explore the complex interplay between culture, youth health, and gender empowerment regarding HIV/AIDS risk within Inuit communities, and determine research priorities for a multi-year study. There is an urgent need for a clearer picture of the dynamics and epidemiology of HIV risk among Inuit in Canada. Current Inuit HIV data tends to get lost among Aboriginal or broader Canadian statistics and under-represents the true situation for Inuit in Canada. This research seeks to contribute to this understanding and hopes to guide the development of sustainable community based participatory options for HIV/AIDS interventions that are sensitive to the challenges of health promotion and health care provision in Northern communities. The project employs a community-based research methodology involving direct participation from Inuit organizations and community members. Moreover, on account of the barriers related to testing in small remote communities (lack of anonymity, stigma and discrimination, lack of access to care upon receipt of a positive test, lack of AIDS Service Organizations in the North), this community-based research methodology provides an important opportunity to build capacity for health care providers and to improve access to education, testing (anonymous testing with pre- and post-test counselling), diagnosis, care, treatment and support.

Table 8 Nunavut Project Summary Characteristics

	Year	Source	Population Studied	Type of Study	Project Funder
1	2007-2009	Aboriginal community-based research capacity-building initiative Canada	Aboriginal communities in Eastern Canada and Nunavut	CBR capacity-building project	CIHR
2	2007-2008	Strengthening community-based approaches to HIV/AIDS education, screening, and treatment among Canadian Inuit youth	Inuit Communities in Nunavut and Quebec	Interplay between culture, youth health, and gender empowerment regarding HIV/AIDS risk within Inuit communities	CIHR

Northwest Territories and Yukon

Project Title: Decision tool for evidence-based planning of AIDS prevention programs

Research Team: Neil Andersson (PI), Jim Martin (CI), Steven Paul Mitchell (CI), Beverley J Shea (CI), Cecilia Zoe-Martin (CI)

Partners: CIHR

Abstract: Leadership among the Tlicho communities of NWT has chosen to make prevention of STIs and HIV a priority health issue. The Tlicho, however, still need to improve how they use evidence to create and implement programs that will be effective and sustainable. Simply put, there is too much existing information around STIs and HIV/AIDS for local community programmers to digest. We propose to identify, to develop and to refine effective and efficient methods to implement evidence-based STI and HIV prevention policy and planning in the Tlicho region through a community customized decision tool. First, we will examine the feasibility and effect of an accessible evidence base for the implementation of evidence-based STI and HIV prevention policy and programs relevant to the Tlicho and other Aboriginal communities. Secondly, we will conduct community-led customization of an existing knowledge translation and decision tool. Thirdly, we will provide capacity-building opportunities for community researchers and decision makers on data synthesis and updating and use of the decision-support tool. The project will build upon an existing systematic review of HIV prevention done in South Africa, and an existing decision tool, created with planners from eight southern African countries. We will extend the systematic review to suit the Tlicho with an emphasis on culturally appropriate interventions, local resilience factors, and community strengths that contribute to STI and HIV prevention. The Tlicho will customize the decision tool for their own use, taking into account their own knowledge of what visual tools work best for the people who need to know and act upon the information. This will be done through a reiterative consultative process between the community representatives and the research team. We anticipate that development of prevention models and decision aids will be relevant to other communities and organizations such as CAAN and the Public Health Agency of Canada.

Project Title: Community-coordinated Research as HIV/AIDS Prevention Strategy in Northern Canadian Communities

Research Team: Karen Edwards (PI), Steve Mitchell (CI), Nancy L. Gibson (CI), Jim Martin (CI), Cecilia Zoe Martin (CI)

Partners: Tlicho Community Service Agency (TCSA), Canadian Institute for Energy Training (CIET)

Abstract: The Tlicho Community Services Agency's (TCSA) Healing Wind Strategy identifies a number of activities and interventions to address the prevention of STI/HIV/AIDS in the Tlicho region of the Northwest Territories of Canada. As a part of this strategy, the TCSA and CIET facilitated research to develop a foundation for interventions targeting sexually transmitted infections. The project recruited and trained community-based researchers who conducted a research survey on sexual health attitudes and behaviours in the four Tlicho communities, covering 65% of the population above 9 years of age. The research process, outcomes, and the strategic plan that arose from the research findings produced a clear framework for interventions that are grounded in the community, but could also influence national and territorial policy. The approach may be relevant in other settings.

Table 9 Northwest Territories Project Summary Characteristics

	Year	Source	Population Studied	Type of Study	Project Funder
1	2008-2010	Decision tool for evidence-based planning of AIDS prevention programs	Tlicho communities of the Northwest Territories	Identify, develop and implement effective and evidence-based STI and HIV prevention policy and planning.	CIHR
2		Community-coordinated Research as HIV/AIDS Prevention Strategy in Northern Canadian Communities	Four Tlicho communities	Research survey on sexual health attitudes and behaviours	