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Canadian Aboriginal AIDS Network  
Research Unit: Researching Us to Life

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On Solid Ground: Our Eyes to the Future  
Regina, Saskatchewan  
October 6, 2005

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# Presentation Outline

- Research Unit – What is it?
    - Strategic Direction and Implementation
    - Current Research Projects
    - Proposed Research Projects (in development or under consideration)
    - Research Capacity-Building Projects
  - Community-Based Research and OCAP
  - Knowledge Transfer and Uptake
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# Strategic Direction

- Using principles of OCAP, CAAN should engage in relevant research that effectively addresses if not arrests the epidemic in Aboriginal communities
    - Address unique (i.e., women, two-spirit/youth, etc.) needs in care, treatment and prevention
    - Human rights/legal issues (particularly relevant in the context of treatment)
    - Mental health issues
    - Expand research efforts to prison settings
    - Compare different treatments (traditional medicines and ARV, etc)
    - Support research activities of our member organizations
    - Gather research and assess its utility
    - Use memorandums of understanding in partnerships with academics
    - Develop and continually update research priorities
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# Strategic Direction – Current and Proposed Activity Areas

## **Current**

- Continued involvement in research (both internally developed research projects and when approached by partners, particularly where proposed research is considered relevant). In all cases, research should be community-based and incorporate OCAP principles
- Work with member organizations/individuals to conduct their own research - or capacity-building (i.e., workshops and for the future, work with member groups to develop their own research projects)
- Use research to inform advocacy efforts
- Return findings to communities (research reports)

## **Proposed**

- Aboriginal graduate students (employed as research assistants or as member of research teams – capacity-build)
- Establishing a common advisory committee (ethics and advice)
- Journal watch
- Explore a variety of ways to return findings to community – meaningful (i.e., fact sheets of findings, pamphlets, workshops, etc.)

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# Current Research

- Canadian Aboriginal People Living with HIV/AIDS: Care, Treatment and Support Issues
  - Addressing Homophobia in Relation to HIV/AIDS in Aboriginal Communities
  - The Influences of Stigma on Access to Health Services by Persons Living with HIV/AIDS
  - The Diagnosis and Care of HIV Infection in Canadian Aboriginal Youth
  - Canadian Aboriginal Cultural Competence for HIV/AIDS Health Care Providers
  - Understanding and Responding to Depression Among Aboriginal People Living with HIV/AIDS
  - Mental Health and Wellness Among Aboriginal People Living with HIV/AIDS
  - Needs Assessment of Correctional Health Lodges: Reintegration of Inmates who may be Living with HIV/AIDS
  - Building on the Resilience of Indigenous People in Risk Reduction Initiatives targeting Sexually Transmitted Infections and Blood-Borne Viruses
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# Canadian Aboriginal People Living with HIV/AIDS: Care, Treatment and Support Issues

## **Research Questions**

- To look at use of HIV-related services by Aboriginal identity, geographic region, age, gender, health status, and transmission category
- To look if needs are being met
- To develop practice and policy recommendations based on findings.

## **Progress**

- Final community report available
  - Peer-reviewed journal articles about to begin.
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# Addressing Homophobia in Relation to HIV/AIDS in Aboriginal Communities

## Research Questions

- How can anti-discrimination policies be developed and implemented to address the needs and rights of Two Spirit people who are accessing Aboriginal organizations?
- How can Aboriginal organizations best implement anti-discrimination policies to improve the quality of services for Two Spirit people living with HIV/AIDS?
- To raise awareness in Aboriginal communities on how to address homophobia when it is a barrier to HIV/AIDS prevention and education.

## Progress

- Community report available
  - Writing peer-reviewed journal articles
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# The Influences of Stigma on Access to Health Services by Persons Living with HIV/AIDS

## **Research Questions**

- In what ways does stigma influence access to health services for Aboriginal People living with HIV/AIDS (APHAs)/Persons living with HIV/AIDS (PHAs)?
- What practices in health care organizations are perceived to be stigmatizing by APHAs and PHAs?
- What design features are optimal for the provision of health services?

## **Progress**

- Data collection complete with analysis started and drafting of community report and peer-reviewed journal articles planned for near future
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# The Diagnosis and Care of HIV Infection in Canadian Aboriginal Youth

## Research Questions

- Why do some Aboriginal youth decide to have an HIV test, while others do not?
- How do Aboriginal youth view HIV testing?
- What is the experience of Aboriginal youth when they present for testing?
- What is the relationship between HIV testing and the decision to initiate treatment among Aboriginal youth?
- How do Aboriginal youth make decisions about the care and treatment of their HIV illness?

## Progress

- Data collection complete with analysis started and drafting of community report and peer-reviewed journal articles planned for near future
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# Canadian Aboriginal Cultural Competence for HIV/AIDS Health Care Providers

## Research Questions

- What are the perceptions and lived experiences of APHAs regarding culturally competent health care services? Do these perceptions/experiences differ by region or by primary versus community-based settings?
- What are the views of primary and community-based health care providers regarding culturally competent care in the context of HIV/AIDS? Are there any similarities or differences between the perspectives and practices of primary and community-based health care models?
- How does culturally competent primary and community-based health service influence the perception of an APHA regarding the quality of service?
- In the context of primary and community-based HIV/AIDS programs and services, what health outcomes are perceived to be related to culturally competent care?

## Progress

- Recently funded with ethics application in progress.
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# Understanding and Responding to Depression Among Aboriginal People Living with HIV/AIDS

## **Research Questions**

- To understand the meaning of depression for APHAs
- To identify the challenges in the provision of services to APHAs who experience depression

## **Progress**

- Recently funded
  - Interviewing has began
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# Mental Health and Wellness Among Aboriginal People Living with HIV/AIDS

## Research Questions

- How are feelings of depression subjectively experienced by APHAs? How do they cope? How do participants describe their depression?
- What do participants do about their feelings of depression? How do they cope? What role do traditional approaches to healing play in response to depression among APHAs?
- How do participants relate their feelings of depression to their HIV infection? How do their feelings influence how they manage health care decisions relating to their HIV?
- How do they understand the roots of their depression? How do our participants relate their feelings of depression to features of Aboriginal communities in Canada, such as racism, acculturation, the legacies of colonization, and residential school experiences?

## Progress

- Recently funded
  - Interviewing has began
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# Needs Assessment of Correctional Health Lodges: Reintegration of Inmates who may be Living with HIV/AIDS

## **Research Questions**

- What prevalence rates are there for HIV and Hepatitis C within the Correctional system in general, and Aboriginal inmate population in specific?
- What evidence is there for Aboriginal inmates who are either Residential school survivors or inter-generationally impacted?
- What levels of incarceration are there for Aboriginal inmates in federal and provincial institutions across the country?
- What conclusions can be drawn from this data that can support designing interventions for inmates being released to the community via the eight Correctional healing lodges?

## **Progress**

- Literature review has begun
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# Building on the Resilience of Indigenous People in Risk Reduction Initiatives targeting Sexually Transmitted Infections and Blood-Borne Viruses

## **Research Questions**

- Identify resilience factors and behaviors among Indigenous people that protect against STI and BBV infections, including HIV
- Develop community-based interventions to increase resilience of Indigenous populations in regard to STI/BBV infection
- Implement the community-led interventions and develop a framework to assess their impact at the individual, family and community level

## **Progress**

- Proposal developed in collaboration with researchers from New Zealand and Australia and has been submitted for funding consideration.
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# Research Capacity-Building Projects

- Enhancing Dissemination: Including Establishing an Aboriginal Community-Based HIV/AIDS Peer-Reviewed Research Journal, Promoting a Web-Presence and Conference Participation
  - Two Research Technical Assistants (Western/Eastern Canada)
  - Qualitative Data Analysis: Aboriginal CBR Capacity-Building Workshop
  - Community Solutions Workshop: HIV Testing and Care for Aboriginal Youth
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# Proposed Research/Capacity Building

## **Research**

- Sexual Violence, HIV/AIDS and Aboriginal Women
- Two-Spirit Women's Experience of Homophobia in the Context of HIV/AIDS Service Provision
- Increasing Participation of Aboriginal Individuals in HIV Clinical Trials: A Pilot Study

## **Capacity-Building**

- Factors in Service Provision that Promote Well-being for Aboriginal Peoples living with HIV/AIDS who Report Substance Use: a Research Capacity-Building Exercise
  - Research Technical Assistant
  - A Continuing Strategic Approach: Aboriginal CBR Capacity Building Workshop (Involvement in Research)
  - Community Consultation to Design an Intervention to Reduce AIDS Stigma
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# Researching Us to Life

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## Community Based Research and OCAP

Renee Masching and Yvon Allard

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# Researching Us to Life

CAAN describes Community Based Research as;

A form of research whereby Aboriginal community collaboration, direction, participation and commitment are essential.

The goal is to develop culturally-appropriate and methodologically-sound research, analysis, and dissemination strategies that are beneficial and empowering for the participating communities and other stakeholders.

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# Principles of Aboriginal CBR

- Aboriginal people living with, affected by and at risk for HIV/AIDS will be actively included in all aspects of research.
  - Aboriginal participation will be demonstrated in all stages of the research process including but not limited to , needs assessments, identifying research questions, collecting and analyzing data, and reporting and applying the results.
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# Principles of Aboriginal CBR

- The diversity of all Aboriginal communities throughout Canada, when addressing HIV/AIDS, is recognized and honoured. This would include communities defined by constitutional status, geographic region, residency, economic status, gender, sexuality, or cultural/spiritual beliefs, values and practices.
  - All initiatives will reflect and promote a balance between culturally-respectful, traditional ways of gathering information and sound, ethical research methodology. Initiatives will also emphasize partnership, collaboration and flexibility.
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# Key Features of CBR

- The problem originates in the community
  - The goal of research is political/social change
  - Community investigators control problem definition, information gathering, and resulting actions
  - Community investigators and professional researchers are equal partners through the process  
(Wuest & Merritt-Gray, 1997)
  - Consistent with the principle of self-determination in research  
(Scharnch, 2004)
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# CBR and CAAN's Strategic Plan

- Research engagement will be key to effectively addressing and possibly stopping the epidemic.
  - CAAN will strategically produce, support and utilize the most relevant research possible.
  - CAAN will continue to enforce the principles of OCAP
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OCAP

Ownership

Control

Access

Possession

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# OCAP

OCAP is:

A political term that is being used by Aboriginal Peoples to highlight the right to self-determination in the area of HIV/AIDS research

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# OCAP in practice at CAAN

- Assert collective ownership of data
  - Be equally involved from beginning to end in research processes
  - To maintain access to research data
  - To maintain possession of the results of research
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# Researching Us to Life

Community Based Research is:

- Driven by community stakeholders
  - Responsive to community needs and issues
  - A tool for Social Change
  - Creative
  - Possible for all of us to do
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