University of Regina, Faculty of Arts, Community Research Unit *Community-Based Research Showcase November 6, 2015* 

at the Core Ritchie Neighbourhood Centre, Regina



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#### Introduction

 Between 1998 and 2008, women represented 48.8% of all positive HIV test reports among Aboriginal Peoples compared to only 20.6% of positive test reports among women of other ethnicities (Public Health Agency of Canada, 2010). These numbers exclude Ontario and Quebec HIV ethnicity statistics.

- Saskatchewan has seen a substantial increase in new cases of HIV since 2003 and as of 2010 has the highest rates in Canada at twice the national average at 20.8 vs. 9.3/100,000 (Public Health Agency of Canada [PHAC], HIV and AIDS in Canada; Surveillance Report, December 31, 2008).
- The epidemiology of HIV in Saskatchewan is different from the rest of Canada, with 75% of new HIV cases in 2009 predominantly associated with injection drug use.
- Aboriginal women under age 30 account for a disproportionate number of all new HIV-positive cases in the province (Ministry of Health, PHB, 2010)
  - (Saskatchewan Ministry of Health, Saskatchewan's HIV Strategy 2010-2014)

As was shown, Aboriginal women are overrepresented in HIV/AIDS statistics and yet there is a startling lack of gender-specific (sex, lesbian, transgendered), Aboriginal-specific, HIV/AIDS resources, programs and services. The literature also indicates that Aboriginal women are the most marginalized population in Canada. Within this context, it is essential that research contribute towards a deep understanding of the drivers that fuel this reality. Furthermore we must identify the assets within the Aboriginal community that sustain women and contributes to culturally relevant solutions.

#### **Our Goal**

To focus on Aboriginal women with the premise of helping them to develop ways of learning about best practices, community and asset-based solutions that are culturally safe

#### Our Objectives

- 1)Understanding the complex Aboriginal social determinants of health that interact to produce higher rates of IDU, HIV/AIDS and HCV among Aboriginal women, particularly those who are identified as frequently not included and those who have not been tested 2) Developing a model of culturally safe care

#### Our Objectives

- 3) Increasing the research capacity of All Nations
  Hope Network (ANHN)-formerly All Nations Hope
  AIDS Network (ANHAN) and the broader
  Aboriginal community in Regina (pilot site)
- 4) Developing educational videos to accompany the culturally safe care model and enhancing the understanding of cultural safety for Aboriginal women living with HIV, AIDS and HCV

#### **Anticipated Benefits** 1)Benefits to community: capacity building; building a unique model to address root causes of HIV, AIDS and Hep C; knowledge translation/education awareness tools; address bias, stigma, racism and stereotyping

#### **Anticipated Benefits**

2) Benefits to health care practitioners:

to promote positive systemic change;

promote knowledge of Indigenous health needs and priorities;

build positive relationships with Indigenous women to promote engagement in their health care needs and treatment to achieve better outcomes.

#### Indigenous Research Methodologies

i) "The gathering of information and its subsequent use are inherently political. In the past, Aboriginal people have not been consulted about what information should be collected, who should gather that information, who should maintain it, and who should have access to it. The information gathered may or may not have been relevant to the questions, priorities and concerns of Aboriginal peoples. Because data gathering has frequently been imposed by outside authorities, it has met with resistance in many quarters" (RCAP, Vol. 3, Ch. 5, 1996)

#### Indigenous Research Methodologies

- i) Research History
  - -referred to as helicopter research that often marginalized Indigenous communities
  - -experimentation on Indigenous peoples
  - -research conducted without consent
  - -traditional knowledge shared by Knowledge Keepers, Elders, Healers is appropriated without knowledge or consent of the community
  - -research is not beneficial to the community
  - -community is not involved in the design or analysis

Indigenous Research Methodologies
ii) Current Research Concepts and Processes
Concepts - Reciprocity, The Collective, Building
Relationships, Giving Back, Wholism,

Processes – Capacity Building, Community Control, Community Engagement, Collaboration, Cultural Responsiveness

Responsibility, Respect;

Indigenous Research Methodologies ii) Current Research Concepts and Processes OCAP – developed in 1998, it is a political response to colonial approaches to research and information management (NAHO, 2004) OCAP refers to **O**wnership, **C**ontrol, **A**ccess and Possession

Ownership — refers to the relationship of a First Nations community to its cultural knowledge/data/information. The principle states that a community or group owns information collectively in the same way that an individual owns their personal information. It is distinct from stewardship. The stewardship or care taking of data or information by an institution that is accountable to the group is a mechanism through which ownership may be asserted.

Control – the aspirations and rights of First Nations eople to maintain and regain control of all aspects of their lives and institutions extend to research, information and data. The principle of control asserts that First Nations people, their communities and representative bodies are within their rights in seeking to control all aspects of research and information management processes which impact them. First Nations control of research can include all stages of a particular research project – from conception to completion. The principle extends to the control of resources and review processes, the formulation of conceptual frameworks, data management and so on.

Access – First Nations people must have access to information and data about themselves and their communities, regardless of where it is currently held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized formal protocols

**Possession** — while ownership identifies the relationship between a people and their data in principle, possession or stewardship is more literal. Although not a condition of ownership, per se, possession (of data) is a mechanism by which ownership can be asserted and protected. When data owned by one party is in the possession of another, there is a risk of breach or misuse. This is particularly important when trust is lacking between the owner and possessor.

Indigenous Research Methodologies iii) Digging Deep Research Methodologies

Community engagement through inclusion of all community members and respecting diversity

Cultural safety through the guidance of Elders and ceremonies and through the adherence of respect for individual spiritual beliefs as well as acknowledgement of the need for wholistic processes

Reciprocity through the acknowledgement and recognition of research participants' contributions



CBRNs (Community-Based Research Navigators) i)Duties - interviews, involved with planning, development, delivery, monitoring and evaluation of the research project as outlined in the work plan as well as offer access to traditional healing and holistic health services and programs for Aboriginal women with HIV, AIDS or HCV who wish to access them

ii) Perspectives

#### Conclusion

The social determinants of health for Aboriginal women intersect in common yet very individualistic ways.

Through our process, it is hoped that we will reveal the unique story of each woman who has participated in the project. With their stories, the women will help heal our communities for generations to come.