



Looking Forward, Standing Together:

A Provincial Strategy for Community-Based Research in BC

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Presentation delivered by:

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A signpost with three directional signs: INTEGRITY, COMMITMENT, and TRUTH. The signpost is a vertical metal pole with three signs attached. The top sign points left and says 'INTEGRITY'. The middle sign points right and says 'COMMITMENT'. The bottom sign points left and says 'TRUTH'. The background is a clear blue sky.

CBR as Decolonizing Research

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Aboriginal HIV in Context

- 2008** – The estimated new HIV infection rate for Aboriginal people was 3.6X higher than NAP
- 2008** - Aboriginal peoples comprised 13.9% of reported AIDS cases that noted ethnicity
- 2008** – 32.6% of Aboriginal people testing positive for HIV were < age 30 and almost half were women

Aboriginal HIV in Context

In addition to being identified by the *Federal Initiative to Address HIV/AIDS in Canada* as one of eight target populations, Aboriginal peoples are also over-represented in other target populations, including: people who use injection drugs, prison inmates, youth at risk, and women at risk.

Aboriginal HIV Research in Context

- ☹ Between 2000 and 2010, CIHR funded just 47 research projects with a direct focus on HIV among Aboriginal Peoples.
- ☹ The majority of the awards represent community-based, doctoral and master's projects respectively
- ☹ Only 6 explore the domain of health services
- ☹ Only 5 incorporated capacity building

Colonizing Research defined

The development, support and expansion of research **ON** Indigenous communities rather than **WITH** Indigenous communities.

A process whereby **authority** and **control** is claimed by researchers, which creates inequities for Indigenous people.

Colonizing Research...

- ✧ Puts pressure on Aboriginal communities to support research
- ✧ Supports research agendas directed by non-Aboriginal people
- ✧ Produces research results that promote stigmatization and stereotyping of Aboriginal peoples
- ✧ Leads to misinterpretation of traditional knowledge and practices.

Colonizing Research...



- ✧ Owns Aboriginal community data
- ✧ Determines who has access to Aboriginal community data
- ✧ Controls the analysis, interpretation and reporting of Aboriginal research

Legacy of Colonizing Research

Researchers' "*unequal power [in] defining, essentializing, labeling and thus alienating the other*" (Smith, 2007), leads to distrust, which...

Creates a *cultural filter* for interpreting:

- ✧ Lack of meaningful community involvement
- ✧ Lack of community benefit
- ✧ Lack of informed community consent

TRI-COUNCIL POLICY STATEMENT

A central vertical signpost with three directional signs. The top sign points up and to the left, the middle sign points right, and the bottom sign points down and to the left. The signs are white with black text. The background is a clear blue sky.

INTEGRITY

COMMITMENT

TRUTH

**ON RESEARCH INVOLVING ABORIGINAL
PEOPLES**

Background

- ❖ Most federal funding for academic research is through three granting councils: SSHRC, NSERC, CIHR
- ❖ In 1998, the three councils agreed on a policy statement called “Ethical Conduct for Research Involving Humans”
- ❖ Universities require virtually all research involving human subjects to be reviewed according to this Tri-Council Statement, whether funding comes from one of the councils or not

Background (cont)

A signpost with four directional signs: 'INTEREST', 'COMMITMENT', 'TRUTH', and 'TRUTH'. The signpost is a vertical metal pole with four signs attached. The signs are white with black text. The top sign is 'INTEREST', the middle sign is 'COMMITMENT', and the bottom two signs are 'TRUTH'. The signpost is set against a light blue background.

- ✧ Until recently, the Tri-Council Statement contained a Section 6, “Research Involving Aboriginal Peoples” but this section was recognized to be incomplete
- ✧ Since 2003, the three councils have been committed to working on a revision to Section 6, which is now Chapter 9.
- ✧ CIHR took the lead in addressing the issues from the perspective of research in the health field

Tri-Council Guidelines

A signpost with three directional signs: INTEGRITY, COMMITMENT, and TRUTH. The signpost is a vertical metal pole with three white signs attached. The top sign points left and says 'INTEGRITY', the middle sign points right and says 'COMMITMENT', and the bottom sign points left and says 'TRUTH'. The background is a light blue gradient.

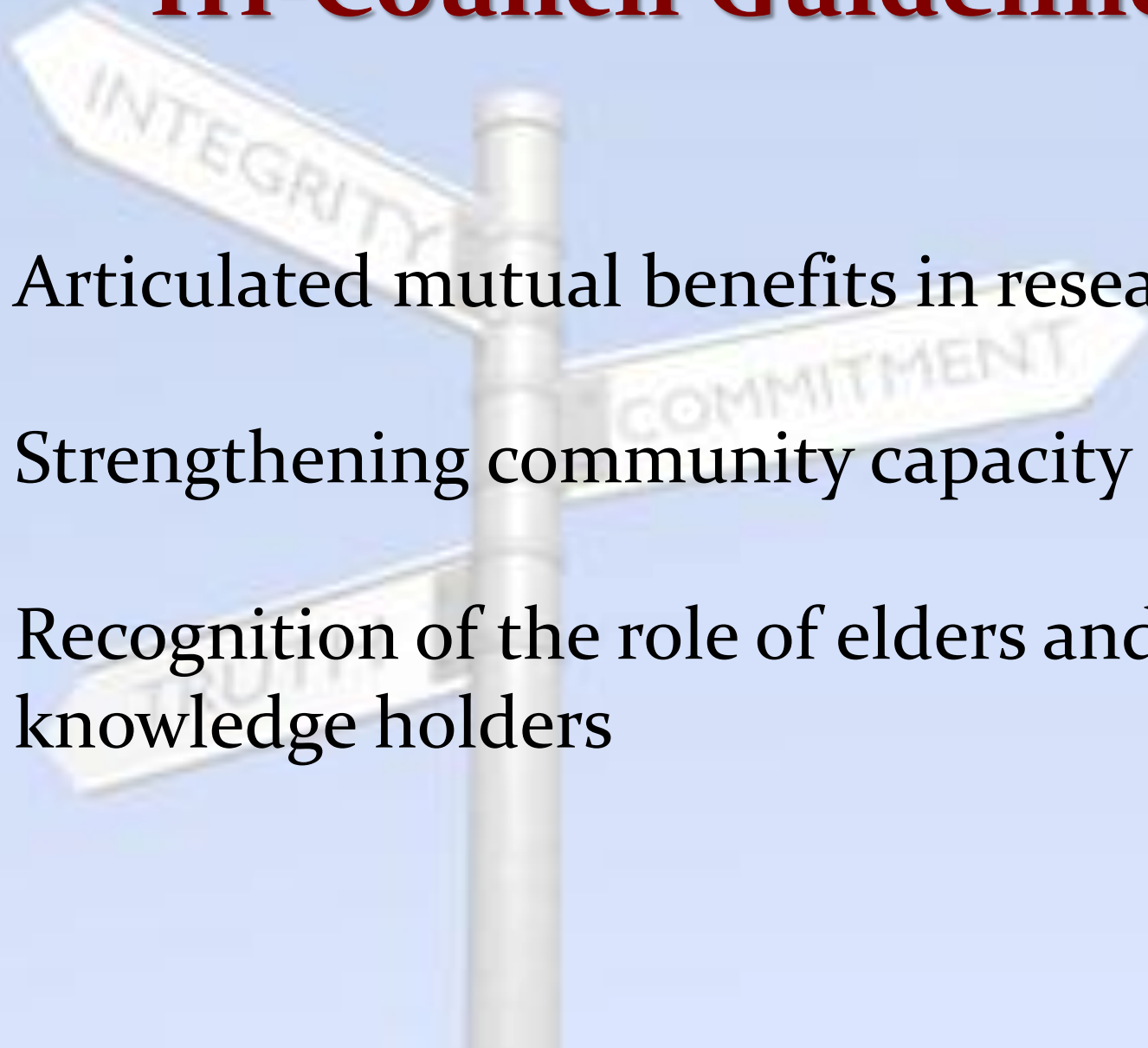
- ❖ Aboriginal communities should be engaged in the research process.
- ❖ Respect for First Nations, Inuit and Métis governing authorities.
- ❖ Engagement with organizations and communities of interest.

Tri-Council Guidelines

A signpost with three directional signs. The top sign points up and left, labeled 'INTEGRITY'. The middle sign points right, labeled 'COMMITMENT'. The bottom sign points down and left, with the word 'QUALITY' partially visible. The signpost is a vertical metal pole.

- ✧ Recognizing diverse interests within communities
- ✧ Critical inquiry
- ✧ Respect for community customs and codes of practice
- ✧ Collaborative Research Agreements

Tri-Council Guidelines

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- A signpost with three directional signs: INTEGRITY, COMMITMENT, and TRUTH.
- ❖ Articulated mutual benefits in research
 - ❖ Strengthening community capacity
 - ❖ Recognition of the role of elders and other knowledge holders

OWNERSHIP

CONTROL

ACCCESS

POSSESSION

Origin of OCAP

A signpost with three directional signs: 'INTEGRITY' at the top, 'COMMITMENT' in the middle, and 'HEALTH' at the bottom.

In 1998 - originally expressed as OCA by the National Steering Committee of the First Nations and Inuit Regional Longitudinal Health Survey (RHS).

The Principles of OCAP* Ownership

An Aboriginal “community or group owns information collectively in the same way that an individual owns their personal information”.

*National Aboriginal Health Organization

Control

Aboriginal Peoples, communities and representative bodies control all aspects of research processes that impact them.

This principle extends to control of resources and review processes, the formulation of conceptual frameworks, and data management.

Access

Aboriginal “people must have access to information and data about themselves and their communities, regardless of where it is currently held...”

To manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized, formal protocols.”

Possession

“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.”

“Although not a condition of ownership per se, possession (of data) is a mechanism by which ownership can be asserted and protected”.

Why I do ACBR

- ❖ To de-colonize research
- ❖ To engage diverse knowledge systems and research practices (*two-eyed seeing, the ethical space*).
- ❖ To ensure community engagement.
- ❖ To focus on community-articulated needs
- ❖ To reinforce the lesson I learned in primary school:
 - ❖ *Play nice !!!*

A signpost with four directional signs: INTEGRITY, COMMITMENT, TRUTH, and RESPECT. The signpost is a vertical metal pole with four white signs pointing in different directions. The signs are slightly blurred and the background is a light blue sky.

Aboriginal CBR is an important component of **self-determination**, which is a key determinant of Aboriginal health.

We all have an obligation to **de-colonize** the research process.

I honour my ancestors



Wela'lin ~ Thank You