

DNA on Loan: Canadian Approaches to Genetic and Genomics Research with Aboriginal Peoples



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**Secretary's Advisory Committee on Genetics,
Health, and Society
Genomic Data Sharing Session**

Aboriginal Health in Canada

- **Known health disparity**
 - Greater burden of chronic disease, infectious disease, nutritional deficiency
 - Shorter life spans
- *Burden of disparity has much broader base than simply human genome variation*

*But genetic factors also contribute
Not to explore the comprehensive determinants of health
creates more disparity*



Around the world indigenous groups are asking for genetics research to be done differently

- Dalton R, Tribe blasts 'exploitation' of blood samples. *Nature*, 2002:14;420(6912):111.
- Couzin-Frankel J. DNA returned to Tribe raising questions about consent. *Science* April 30 2010:328 (5978)558
- Couzin-Frankel J. Researchers to Return Blood Samples to the Yanomamö *Science*. June 4, 2010:328(5983)1218

The last decade: Building relationships between policy makers, researchers and aboriginal groups

- The question: Can biomedical (genetic) research be carried out in a collaborative manner acceptable to First Nations, Metis and Inuit?
- CIHR-IAPH



Indigenous Peoples Concerns with Genetic Research

- Displaced research funding
- Concerns with commercial/academic exploitation
- Issues of trust
- “helicopter research”
- Research results may be stigmatizing



Cultural Issues: The Impact of Genetic Study

- *“To us, any part of ourselves is sacred. Scientists say it’s just DNA. For an Indian, it’s not just DNA, it’s part of a person, it is sacred, with deep religious significance. It is part of the essence of a person”* Frank Dukepoo, Interview, San Francisco Chronicle, 1998

Discussions

- 1) National Council of Ethics in Human Research (NCEHR):
Research involving individuals and communities:
Genetics as a focus. (Ottawa, November 1999)
- 2) NCEHR: Canadian Commission for UNESCO, Health
Canada: Continuing the dialogue: Genetic Research with
Aboriginal Individuals and Communities. (Vancouver,
January 2001)
- 3) CIHR:IAPH An exploratory workshop on a tribal controlled
DNA bank. (Vancouver, August 2001)
- 4) CIHR:IAPH Part 2 An exploratory workshop on a tribal
controlled DNA bank. (Tofino, January 2002)

Topics of discussion

- Cultural/historical perspectives of blood sampling (Dene, Pueblo, Native Hawaiian)
- Canadian Genetic Research in aboriginal communities
- Research policy and guidelines in Canada
- Case Studies
- Community perspectives
- Legal perspectives (cultural property?)
- DNA sampling and storage
 - “tribal controlled DNA bank” Dr. Merv Tano

Why was there a disconnect with expectations? Biomedical Model of Research Vs Participatory Research

- Often disease focused
- Purpose is to add to body of scientific knowledge
- Subjects are recruited (necessary to provide data)
- Participants (subjects) little voice in the research process or results
- Subjects often waive rights of profit while participating (no benefit sharing)

Where is the disconnect with expectations?

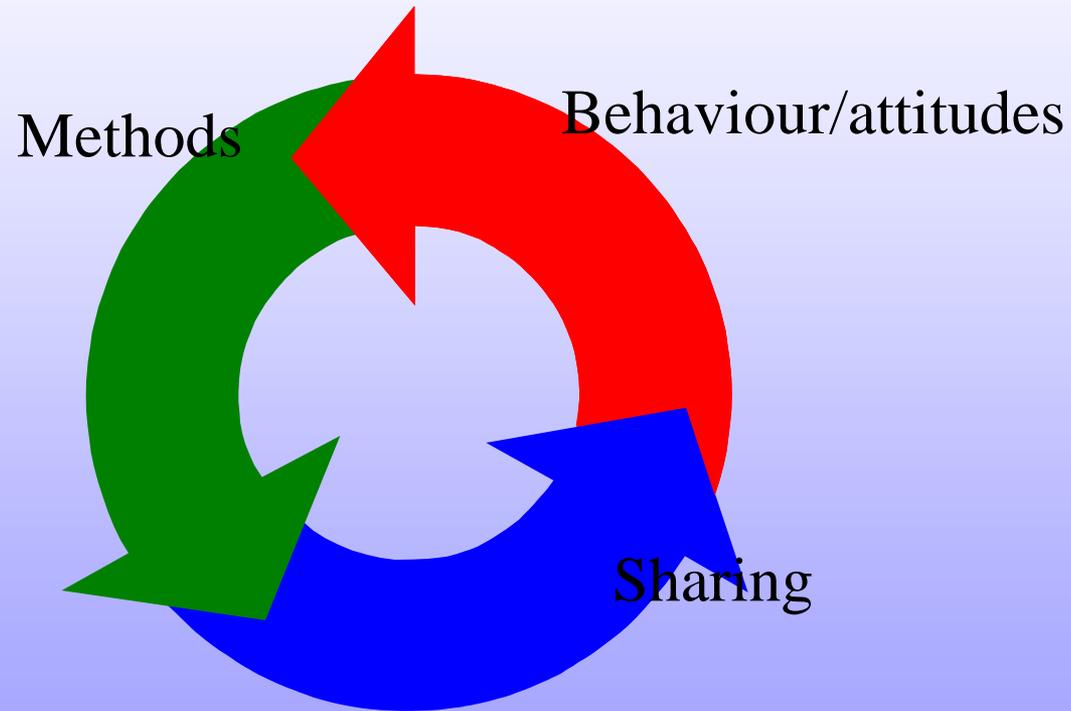
- Data and samples are ‘owned’ by the researcher and sometimes sponsor (rarely shared with subjects)
- Results are published in peer reviewed journals, but not specifically directed to or shared with subject/community involved in research
- *Expectations of aboriginal community and research community may be at a divide.*

Canadian guidelines defining ethical research in aboriginal communities

- Dene tracking: A participatory research process for dene/metis communities (1993)
- Inuit Tapirsat background paper on negotiating relationships in the north (1994)
- Kahnawake Code of Research Ethics (1997)
- Akwasasene Research Code of Ethics (1998/99)
- Cree Board of Health and Social Services of James Bay Code of Research Ethics (2001)
- Protocols and Principles For Conducting Research in an Indigenous Context (Uvic)
- Tri-council Policy (Chapter 9)

None of these specifically addressed the use of biological samples

Community Based Participatory Research



Community needs
Respect for beliefs
Education
Capacity development

Whose Reality Counts?
Robert Chambers-1997

DNA on Loan: principles for the use of research samples for DNA for research in aboriginal populations

- Specimen collection, storage, uses and destruction should be in accordance with the wishes of the community
- All blood and tissues accepted for research will be considered the property of the donor/community involved and thus will be considered *on loan* to the researcher



CIHR GUIDELINES FOR HEALTH RESEARCH INVOLVING ABORIGINAL PEOPLE



CIHR Guidelines for Health Research Involving Aboriginal Peoples

- **Article 1:** A researcher should understand and respect Aboriginal world views
- **Article 2:** A community's jurisdiction over the conduct of research should be understood and respected.
- **Article 3:** Communities should be given the option of a participatory-research **approach**.

CIHR Guidelines for Health Research Involving Aboriginal Peoples

- **Article 7:** Aboriginal people and their communities retain their inherent rights to any cultural knowledge, sacred knowledge, and cultural practices and traditions, which are shared with the researcher.
- **Article 9:** Research should be of benefit to the community as well as to the researcher.
- **Article 10:** A researcher should support education and training of Aboriginal people in the community, including training in research methods and ethics.

Knowledge dissemination

- **Article 11.2:** A researcher should, to the extent reasonably possible, translate all publications, reports and other relevant documents into the language of the community.
- **Article 11.3:** A researcher should ensure that there is ongoing, accessible and understandable communication with the community.

Secondary Use of data/samples

- **Article 12.3:** Secondary use of data or biological samples requires specific consent from the individual donor and, where appropriate, the community.
- **Article 12.4:** Where the data or biological samples are known to have originated with Aboriginal people, the researcher should consult with the appropriate Aboriginal governing body before initiating secondary use.

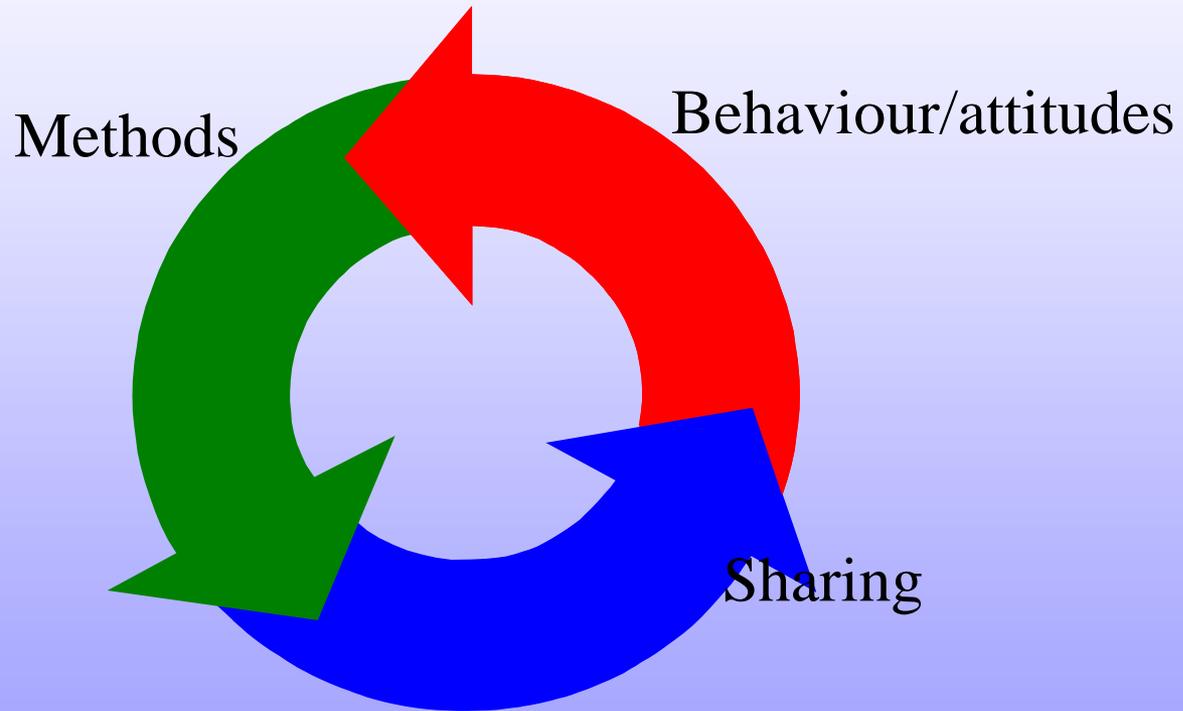
CIHR Guidelines for Health Research Involving Aboriginal Peoples

- **Article 13: Biological samples should be considered ‘on loan’** to the researcher unless otherwise specified in the research agreement.
 - Subject to the terms of the research agreement with their community, biological samples from Aboriginal participants should be considered “on loan” to the researcher, analogous to a licensing arrangement, and this should be detailed in the research agreement.

Interpretation and acknowledgement

- **Article 14:** An Aboriginal community should have an opportunity to participate in the interpretation of data and the review of conclusions drawn from the research to ensure accuracy and cultural sensitivity of interpretation.
- **Article 15:** An Aboriginal community should, at its discretion, be able to decide how its contributions to the research project should be acknowledged. Community members are entitled to due credit and to participate in the dissemination of results. Publications should recognize the contribution of the community and its members as appropriate, and in conformity with confidentiality agreements.

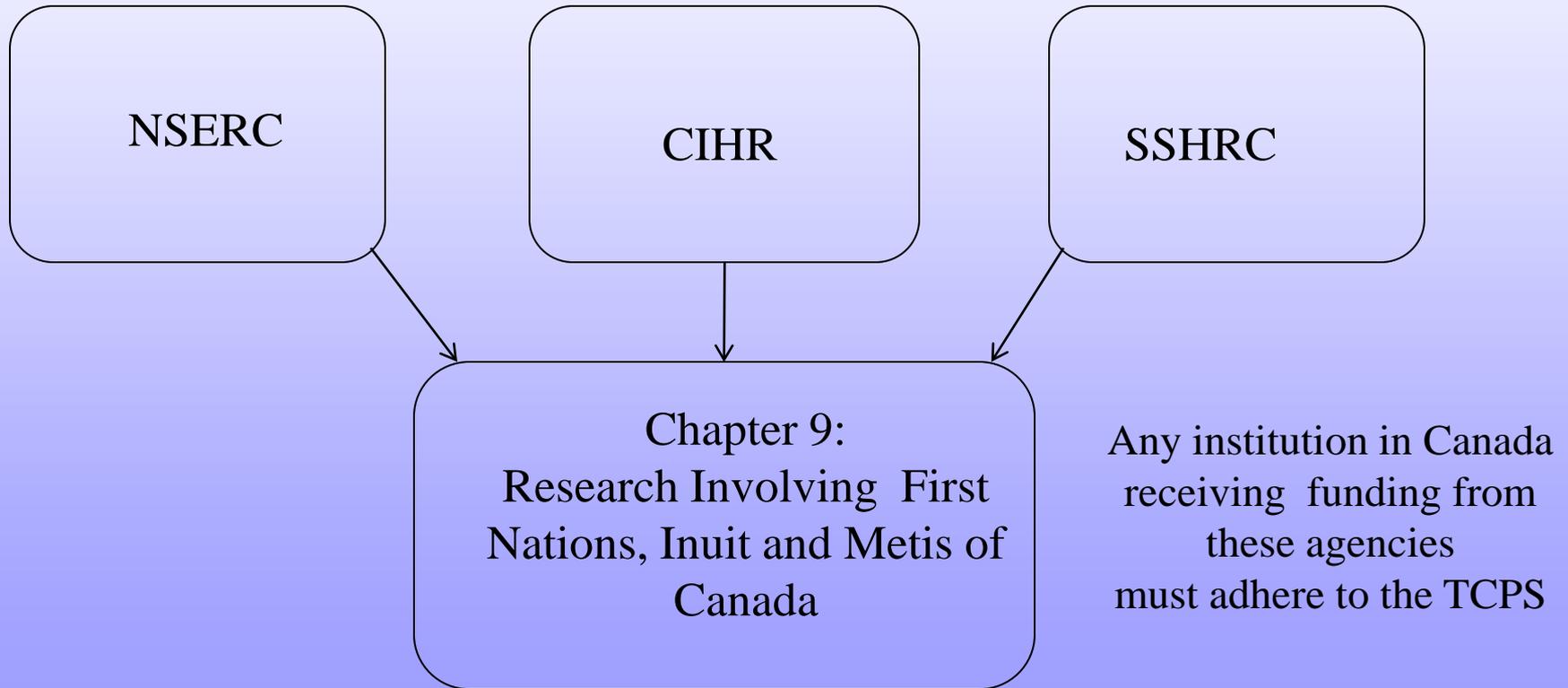
Aboriginal partners become full collaborators in the research: including use of DNA



Community needs
Respect for beliefs
Education
Capacity development

Research results
Publications
Secondary research

Tri-council Policy Statement



“With respectful dialogue and considerable hard work, traditional Aboriginal values can co-exist with mutually productive connections between genetic researchers and communities” Joe Kaufert, Kathy Glass

*Doris Cook, Laura
Commanda, Joseph
Kaufert, Kathy
Glass, Barb
McGillivray,
Francine Romero,
Jeff Reading*



Community Genetics
Research Program
UBC-Victoria

Long QT Syndrome in a First Nations
Community of Northern British Columbia
(CIHR)

Primary Biliary Cirrhosis in the Pacific
North West First Nations (CLF)

Genetic and Nutrient determinants of
congenital heart defects in the Inuit of
Nunavut (CIHR)

The prevention of infant mortality-
Should Newborn screening be carried out
for the CPT1a P479L variant (CIHR)

