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# DNA on Loan Forum

## Forum Report



Canadian Institutes of Health Research    Instituts de recherche en santé du Canada

Canada

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## Executive Summary

The “DNA on Loan: Exploring Biobanking with Indigenous Values” forum was held to explore the issues surrounding long term storage of biological samples when research involves the Indigenous Peoples of Canada. We built from the former CIHR Guidelines for Health Research Involving Aboriginal People (2009), and the current Canadian Tri-council Policy Statement: Ethical Conduct for Research Involving Humans (Chapter 9, 2014). The objectives were to provide national and international views on good practice and policy in this area and encourage dialogue that provided background for enhancing our current Canadian policy.

Sixty participants attended the 2-day forum. Participants came from a wide range of backgrounds and included members and elders of Indigenous communities, Indigenous researchers, scientists and researchers who work with Indigenous communities, and government employees. The majority of participants were Indigenous, including among others, Métis, Inuit, First Nations, Maori, Hawaiian Native, and Australian Aboriginal.

Day 1 of the meeting included presentations by experts on genomics, biobanking, ethical issues, and conducting research with Indigenous communities. Dialogue was encouraged alongside the presentations and during a Networking dinner that followed.

Day 2 was formatted as an open mic, where participants were able to comment on topics, ask questions and voice concerns and ideas. Key points from the forum include:

- There are inequities in access and utilization of healthcare services and research for Indigenous people in Canada.
- Research that includes biobanking components is being introduced in many jurisdictions (Australia, New Zealand, Canada, US etc). Some key points identified that need to be considered:
  - Guiding principles must be developed with involvement from the communities and must be respected
  - Indigenous voices need to be part of the process
  - Cultural beliefs and practices must be respected and incorporated into the research
  - Consent needs to be extremely clear as to the current and future use of the samples, with opt-out options
  - It is vital to include Indigenous people as participants (rather than subjects) in research activities that involve the collection of biological samples from inception.
  - These ethical practices must continue to be built on, as historically there have been issues with governance, stewardship, respect, ownership, access of biological samples and control of data
- There are excellent examples of research with Indigenous people internationally and nationally that include biobanking and can be used as models for policy in Canada.
- Research that involves biological samples from Indigenous people must take into account views on sacredness of the human body, spirituality. Researchers must commit to working with members to integrate the culture, ideals and traditions upheld by these communities into the research.

## Context

### DESCRIPTION AND MORE DETAILED OBJECTIVES

Research involving biobanks and genome sequencing is common in mainstream science. This forum, held in Wendake May 16-17, 2016, offered the opportunity to share diverse Indigenous best practices regarding current Canadian standards for research that involves biological samples (<http://biobanking.mcgill-cihr-ig.ca>) and [consider further development of policy](#). Balancing the potential harms with the potential benefits of such research requires careful consideration when research involves indigenous peoples. Historically, there are examples where genetic research was extremely helpful influencing diagnosis and care within communities (diabetes, Long QT syndrome LQTS)) and, while not discussed in detail, well known and published examples where such research has caused harm. Such examples include lack of informed consent regarding the secondary use of the sample, failure to incorporate culture and sacredness into methodology and research process, not involving communities adequately in research study (indeed not consulting in any capacity), and not sharing results with members of the community leading to loss of ownership of the data.

The ultimate goal of this workshop was to renew a dialogue started several years ago (see Arbour and Cook and CIHR Guidelines 2007-2010) promoting a common understanding of the issues surrounding biobanking and consider how the issues might be addressed through existing and future policy development. It is important to note that the objective of this workshop was to share and discuss how to conduct biomedical research involving Indigenous people in a culturally appropriate manner considering whether current protections are sufficient with advancing genomic technologies, longitudinal and multi-site cohorts. Current international perspectives were sought to inform Canadian stakeholders. Discussion about whether or if such research should be conducted were outside of the scope of the event which was aimed at ensuring safe practice when genetic/genomic research is carried out. However, we firmly believe that such discussions are important, need to be on-going, and all decisions need to be respected. For the detailed agenda of the workshop, please refer to Annex 1.

This event was supported by the Canadian Institutes of Health Research (CIHR) Institute of Aboriginal Peoples' Health (IAPH), CIHR Institute of Genetics (IG) and CIHR Institute of Nutrition, Metabolism and Diabetes (INMD).

The following summary has been divided into relevant themes and is based on notes taken during the event and reviewed by Scientific Directors MK, PL and co-chairs of the Organizing Committee (LA, NC).

## Cultural and Historical Aspects

### Ceremony

- It remains important to begin/end with ceremony and acknowledge the land of the people – the people of Wendake were generous in welcoming us to their land. An opening Prayer was offered by the Chief Konrad Sioui, Huron-Wendat Grand Chief to open the event into a safe space for dialogue.
- Tobacco was offered to all attendees in appreciation
- A Closing prayer concluded the meeting as well

### Acknowledgement of troubled history

- “Warrior gene” (monoamine oxidase A) – a scientific/genetic explanation for violence in the Maori community.
  - The community is very sensitive about this controversy and while open to working with scientists they are still cautious because they feel cultural concerns may not be acknowledged
  - Historically, they have experienced a loss of control over time particularly in regards to research

### Access to healthcare

- Multiple speakers raised the concern with inequities of accessing and utilizing Canada’s healthcare system, specifically for populations that are marginalized and live in remote regions
  - Equal access to healthcare doesn’t exist
  - Why does a postal code determine a patient’s ability to access care?
  - Closing the equity gap important not just in health but in all areas
  - Lack of access to research might increase the inequities in the era of personalized medicine that will rely on integration of genetic and other types of data

## Data and Biobanks

### Explanation of biobanks

- Nadine Caron gave an explanation of biobanks, why they exist and their importance
  - Biobanks are a systematic way to store biospecimens and associated annotated clinical data
  - The data can be used to across the spectrum of medicine from predicting risk for disease, diagnostic tests and

associated prognosis, treatment options and indications, point of care utilization and, risk of drug interactions, to name a few.

- Their use is increasing exponentially
- Biobanks are important for the development of healthcare globally
- NC also discussed how research/clinical applications are being asked for by patients, but there is an absence of research, access and known applicability to these genomic advances for those living in the north, those from rural populations and from First Nations/Indigenous people

### Data Rights/interests

- Another common theme surrounded data rights/interests for the Indigenous communities
- For many Indigenous people, they are not looking for a direct individual benefit but rather are looking to research for how they can contribute to a greater good and for what will make a difference for future generations.
- But questions remain as to Indigenous rights and interests regarding samples, data results and involvement with interpretation (especially in long term studies that may be in effect for generations).
- Indigenous populations continue to strive to direct research and policy when the research involves them.

### Current initiatives

The below are examples of various current initiatives that speakers presented on during the meeting that include a strong Indigenous voice.

#### Canada

- British Columbia: Northern Biobank Initiative (NBI) – Phase 2; focused on the north as generalizability cannot always apply to different population groups; this has the potential for novel findings. This also included specific consultation with First Nations communities regarding a “First Nations Biobank”.
- British Columbia: First Nations Health Authority (FNHA)
  - Chiefs gained control over Aboriginal health services - \$200 million in funding from government
  - Community driven – all activities and info gathering occurs in the region

British Columbia: research into Long QT syndrome type 1 with Gitxan community

- Continuous, ongoing relationship with UBC research team for more than ten years– participatory research, community governance
- Nunavut: Nunavut Tunngavik Inc. (NTI) – Inuit organization has a major role in research and governance
- Manitoba: Health/Wellness, Manitoba Métis Federation
  - Culture based holistic wellness – 8 areas to organize information
  - Community wellness development program
  - Métis Atlas, administration health/social databases
- Ontario: Six Nations of the Grand River – many research projects in collaboration with McMaster and PHRI
  - Ongoing collaboration for over 18 years.
- National: Tri-council policy, chapter 9 (but this was acknowledged as limited for current needs)

### International

- New Zealand: He Tangata Kei Tua Relationship Model for Biobanking with Maori
  - Takoha- a gift with a purpose – to be used for a certain reason, and if not for that purpose, it is to be returned - the gift is the responsibility to look after the tissue.
  - Puts the individual and data in the middle
  - Operations, access, questions (come from community feedback efforts)
- United States: Summer internship in Indigenous Genomics (SING)
  - One week workshop offered annually for Native American students and community members exploring the uses/misuses of genomics and provides training in concepts and scientific methods.
- Australia: SAHMRI – building that provides governance and stewardship for the institute (Indigenous space)
  - Building is designed to look like a jackfruit
  - Separate space for Indigenous samples with separate database
- South Australian Aboriginal Health Research Accord
  - All government agencies are part of this accord which includes community organizations, council of Elders and other contributors
  - Attention to how research is approached– provides high bar of participation and research standards
  - Indigenous community members and council of Elders involved in setting the standards – ahead of the curve



- Australia: PROPHECY – predicting renal ophthalmic and heart events in the Aboriginal community
  - Biobank with blood and other tissue samples
- Australia: Council of elders – highest form of decision-making and consultation; ‘whatever the council says goes’
- Australian Biobanking Initiative (National Centre for Indigenous Genomics) ncig.anu.edu.au
  - Cell phone application to allow individuals to participate in biobanking initiative – provide/decline consent for use of previously collected samples instantaneously on app
  - Samples from previous research including Indigenous populations currently being kept in Australian university in Canberra

## Key Aspects Pertaining to Research with Indigenous Communities

### Partnership

- Theme was present throughout meeting, and there was consistent agreement that Indigenous peoples (individuals, communities) should be included as a research partners
- Community members want to be involved in the process, not simply consulted
- Indigenous partners need to be involved in all aspects of research (research question, data and sample collection, storage, use interpretation, publications and knowledge translation)
- Cultural aspects need to be acknowledged and build cultural foundation including taking part in ceremony/rituals

### Principles for conducting research (suggestions and current practices)

- Develop clear guidelines for biobanking and genomic research *with* Indigenous populations
  - This must be done with the involvement of Indigenous communities and representatives
  - Consider local language needs
- There should be the creation of protocols for research with tissue (where sample is taken, returned and space in between); ‘gifting of responsibility’, DNA on Loan
  - Parameters need to be established during consultation phase as once consent form is complete and accepted, further edits are difficult to make
- Consent – should also consider cultural and spiritual aspects
  - Free prior and informed consent before a sample can be used for research – frames prospective work and can also guide retrospective usage of samples

- Options to opt out must be well stated in consent forms
- Consent forms include future use clauses; forms in general should be more robust/meaningful
- Consider various levels of consent needed (community/tribal council, family, individual)
- Governance structure (indigenous involvement) needs to be developed
- Kawa: New Zealand Guiding Principles consider levels of Comfort, Control, Integrity
- First Nations: Consider OCAP Principles – Ownership, control, access, possession
- Consider Métis knowledge and experience to act on collective health/needs
- Structures and agreements should be in place before biobanking introduced in Inuit regions

### Suggestions and Resources to Enable Research

- Requirement under international law to share benefits of research
- Develop on-going relationships with Indigenous people so they are involved and informed in decision-making process and on-going research
- Involve elders
- Reframe the discussion of issues/health from deficit to wellness
- Make sure info and results are returned to community
- Ensure there are safeguards against potential harm (information that may be used against communities)
- Balance between cultural consideration and scientific advancement
- Need mix of scientists and legal/cultural expertise engaged in research initiatives including biobanking.

### Concerns/issues

While many participants expressed interest in biobanking, concerns and issues with the concept of biobanking and genomics, and, in general, research with Indigenous populations have been raised. Key concerns that were highlighted by participants included:

- Ownership of data
  - Community members expressed concerns about governance, and control/ownership of the data once the samples have been collected and identified that structures need to be implemented to ensure Indigenous communities have control of how the samples/data is used in the long term. Concerns

- have been driven by secondary use of samples and data for reasons not considered in the original consent
- Indigenous voices must be incorporated in the development of protocol, consent forms, research design, data storage, results review, potential of secondary use and other related issues.
- Consent
    - Consent was an issue brought up multiple times, specifically because historically, this has been extremely troublesome especially when considering the frequent lack of consideration for potential future use.
    - Research needs to be explained in terms community members can understand/relate to
    - Language needs to be considered
    - Consent consideration for future use must be included
    - Stipulations for return of sample if requested
    - Opt-out options must be and explained very clearly
    - Governance can become a balancing factor around concerns with consent
  - Sacredness/Indigenous traditions:
    - Research designs are often westernized – there is a need for incorporation of more Indigenous research methodologies
    - Indigenous concerns that research results may lead to commercialization (i.e. making a product)
    - Sacredness of samples must be acknowledged; concept of spirituality must be incorporated in the conversations
    - Respect for the community's intentions and traditions
    - Translation – some do not communicate in westernized languages; therefore, there is a need for translation
      - Must also acknowledge that some words cannot be translated into Indigenous languages (e.g. there is no word for protocol which creates a communication challenge to be addressed with the community)
    - Need to consider incorporation of ceremony for taking/storage/removal/destruction of samples in order to acknowledge the gift, and acknowledge its sacredness
  - Trust
    - Not all communities, nor everyone in participating communities will be comfortable with biobanking or research in general
    - Reconciliation – researchers must acknowledge the history affecting people and land.

- Consider whether biobanking/genetic research fits with the community priorities?
  - Basic health, social, education, economic, etc necessities are currently not being met in many communities – how is the need for basics and the perceived need for research balanced (consider that many communities have food insecurity and lack of clean water)
- Canadian Tri-council policy Chapter 9 was identified as not being adequate – particularly with advancing technologies and moves to multicentred cohort studies.

### Action Items/Next Steps

1. Workshop participants will have the opportunity to share this report with their communities to increase awareness and knowledge about biobanking and potential benefits and harms in order to make informed decisions about their future participation or development of research projects involving biobanking.
2. As CIHR's Ethics Office and Standing Committee on Ethics will be expanding their activities pertaining to indigenous research, follow up will be done to include the key points of the DNA on Loan workshop in their discussions.
3. Vardit Ravitsky will lead discussions about the next revision of the Tri-Council Policy Statement for aspects pertaining to research with indigenous populations Any revisions will have a strong indigenous representation (Communities, Elders Indigenous scholars).
4. While continuing to develop the microbiome initiative, CIHR INMD and CIHR Institute of Infection and Immunity will evaluate how to integrate components and values that could enable participation of indigenous communities, should they decide to do so.
5. Summary of this workshop will feed into the development of the indigenous component of the Healthy Life Trajectories Initiative that IAPH is co-developing in collaboration with CIHR Institute of Human Development, Child and Youth Health.

## Annex 1: Agenda

### Day 1: May 16<sup>th</sup>, 2016 | Presentations

- |   |  |
|---|--|
| <p>Welcome and Elder's Prayer</p> <ul style="list-style-type: none"> <li>• Oney Maher, Wendat Elder</li> <li>• Konrad Sioui, Huron-Wendat Grand Chief</li> <li>• Tobacco Ties</li> <li>• Symposium Speaker and Attendee Introductions</li> </ul>  | 8:00-8:30  |
| <p>Presentations</p> <ul style="list-style-type: none"> <li>• Setting The Scene and Presentations             <ul style="list-style-type: none"> <li>○ Nadine Caron, University of British Columbia (UBC)</li> <li>○ Francois Gros-Louis, Université Laval</li> </ul> </li> <li>• Panel   International Experiences             <ul style="list-style-type: none"> <li>○ Maui Hudson [Maori], University Of Waikato</li> <li>○ Mervyn L. Tano [Hawaiian], International Institute for Indigenous Resource Management (IIIRM)</li> <li>○ Ngiare Brown, South Australian Health and Medical Research Institute</li> </ul> </li> <li>• Panel   Canadian Perspectives             <ul style="list-style-type: none"> <li>○ Warner Adams, Deputy Chair, First Nations Health Council</li> <li>○ Sharon Edmunds Potvin, Nunavut Tunngavik Inc.</li> <li>○ Scot Nickels, Research Advisor, Nunavut Tunngavik Inc.</li> <li>○ Sheila Carter, Director, Health And Wellness, Manitoba Métis Federation</li> </ul> </li> <li>• Panel   Mutual Expectations In Research: Building Trust In Partnership             <ul style="list-style-type: none"> <li>○ Julie Bull [Nunatukavut], University Of Victoria</li> <li>○ Julie Morrison [Gitxan], Gitxan Health</li> <li>○ Laura Arbour, University Of British Columbia (UBC)</li> <li>○ Bonnie (Darlene) Davis, White Pines Wellness Centre</li> </ul> </li> </ul> | <p>8:30-9:30</p> <p>9:30-12:00</p> <p>13:30-15:00</p> <p>15:30-17:00</p> |

- Dr. Sonia Anand, McMaster University And  
Population Health Research Institute

## Day 2: May 17th, 2016 | Breakout Sessions

Introduction	8:30-10:00
<ul style="list-style-type: none"><li>• Laura Arbour</li><li>• Alexandra King</li><li>• Ngiare Brown: Australian Biobanking Documentary</li></ul>	
Sacredness	10:00-11:00
<ul style="list-style-type: none"><li>• Katherine Whitecloud</li></ul>	
The Human Biome & Microbiome	11:00-11:45
<ul style="list-style-type: none"><li>• Phil Sherman</li></ul>	
Epigenetics	11:45-12:30
<ul style="list-style-type: none"><li>• Paul Lasko, CIHR Institute Of Genetics</li></ul>	
Summary	12:30-13:00
<ul style="list-style-type: none"><li>• Doris Cook</li></ul>	

## Annex 2: Participants

Last Name	First Name	Roles	State/Province	Country	Position	Department	Institution
<b>Adam</b>	Warner	participant, speaker		Canada	Deputy Chair		(BC) First Nations Health Council
<b>Adams</b>	Evan	participant	British Columbia	Canada	Chief Medical Officer		First Nations Health Authority
<b>Adatia</b>	Safina	Staff		Canada	Project Officer	Institute of Genetics	Canadian Institute of Health Research
<b>Anand</b>	Sonia	participant	Ontario	Canada	Professor	Medicine and Epidemiology	McMaster University and Population Health Research Institute
<b>Arbour</b>	Laura	participant, speaker, staff	British Columbia	Canada	Professor	Medical Genetics	University of British Columbia
<b>Aubin</b>	Jane	participant		Canada	Chief Scientific Officer and Vice-President, Research, Knowledge Translation and Ethics		CIHR
<b>Bachiri</b>	Darlene	participant		Canada			
<b>Ballard</b>	Myrle	participant	Manitoba	Canada	Post Doctoral Fellow	Faculty of Health Sciences	University of Manitoba
<b>Boswell</b>	Brooke	participant		Canada	MSc, Community Health Sciences		UNBC
<b>Brown</b>	Ngiare	participant, speaker	New South Wales	Australia	Consultant - Culture, Research and Bioethics	Wardliparingga Aboriginal Research Unit	South Australian Health and Medical Research Institute
<b>Bruce</b>	Sharon	participant	Manitoba	Canada	Associate Professor	Community Health Sciences	University of Manitoba
<b>Bull</b>	Julie	participant, speaker	Ontario	Canada		Public Health and Social Policy	University of Victoria
<b>Burgess</b>	Michael	participant	British Columbia	Canada	Professor	W. Maurice Young Centre for Applied Ethics	University of British Columbia

## DNA on Loan Symposium

<b>Caron</b>	Nadine	participant, speaker		Canada			University of Northern British Columbia
<b>Carter</b>	Sheila	participant, speaker	Manitoba	Canada	Director	Health & Wellness	Manitoba Metis Federation
<b>Cook</b>	Doris	participant, speaker	Florida	United States			Akwesasne Elder
<b>Cullum</b>	Jodi	participant	Alberta	Canada			CIHR Institute of Cancer Research
<b>Davis</b>	Bonnie (Darlene)	participant, speaker	Ontario	Canada	Research Clinical Staff	Six Nations Health Services	White Pines Wellness Centre
<b>Dennis</b>	John	participant	Alberta	Canada	consultant in Human Health		Fort McKay First Nations
<b>Edmunds Potvin</b>	Sharon	participant, speaker		Canada			
<b>Graham</b>	Bonita (Bonny)	participant	Alberta	Canada	Director of Nursing (RN)	Nursing	Maskwacis Health Services
<b>Gros-Louis</b>	Francois	participant, speaker	Quebec	Canada	Associate professor	Surgery	Laval University
<b>Healy</b>	Bonnie	participant	Alberta	Canada	Operations Manager/Board Member		AFNIGC/IAPH
<b>Henare</b>	Kimiora	participant	Alberta	Canada	Eru Pomare Postdoctoral Research Fellow	Auckland Cancer Society Research Centre	The University of Auckland / University of Calgary (visiting)
<b>Hudson</b>	Maui	participant, speaker		New Zealand	Senior Research Fellow	Maori and Indigenous Governance Centre	University of Waikato
<b>Huisman</b>	Lee-Anna	participant		Canada	Family Medicine Resident		UBC
<b>Irvine</b>	James	participant	Saskatchewan	Canada	Medical Officer Health / Professor Emeritus	North Sask Population Health Unit	University of Saskatchewan



## DNA on Loan Symposium

<b>King</b>	Malcolm	participant, speaker		Canada			CIHR Institute of Aboriginal Peoples' Health
<b>King</b>	Alexandra	participant, speaker	British Columbia	Canada	Physician / Researcher		Lu'ma
<b>L'Hommecourt</b>	Jean	participant		Canada			
<b>Larcombe</b>	Linda	participant		Canada	Assistant Professor	Internal Medicine	University of Manitoba
<b>Lasko</b>	Paul	participant, speaker		Canada			CIHR Institute of Genetics
<b>Lesage</b>	Louis	participant		Canada			
<b>Linn</b>	Kevin	participant	British Columbia	Canada	Senior Policy Analyst		First Nations Health Authority
<b>Maher</b>	Oney	participant, speaker		Canada	Wendake Elder		
<b>Mayotte</b>	Lisa	participant	Saskatchewan	Canada	Community Health Nursing Manager	Community Health	Lac La Ronge Indian Band Health Services
<b>McMullin</b>	Kathleen	participant		Canada			
<b>Mitchell</b>	Steven	participant		Canada			Canadian Institutes of Health Research
<b>Morrison</b>	Julie	participant, speaker	British Columbia	Canada	Health Director		Gitxsan Health
<b>Nahwegahbow</b>	Amy	participant	Ontario	Canada	Senior Project Manager	PEKE	Native Women's Association of Canada
<b>Nelson</b>	Joanne	participant		Canada			
<b>Nickels</b>	Scot	participant, speaker	Ontario	Canada	Director	Inuit Qaujisarvingat	Inuit Tapiriit Kanatami
<b>Picard</b>	Manon	participant	Québec	Canada			
<b>Poirier</b>	Paul	Participant	Québec	Canada	Professor	Faculty pf Pharmacy	Université Laval
<b>Postras</b>	Paulete	participant	Saskatchewan	Canada	Community Participant		First Nations University of Canada and All Nations Hope Network

## DNA on Loan Symposium

<b>Ravitsky</b>	Vardit	participant	Quebec	Canada	Associate Professor	Social and Preventive Medicine	University of Montreal
<b>Richer</b>	Etienne	participant	Quebec	Canada	Associate Director	Institute of Genetics	CIHR
<b>Roulette</b>	Joanne	participant		Canada			
<b>Sanguins</b>	Julianne	participant	Manitoba	Canada	Research Program Manager	Health & Wellness	Manitoba Metis Federation
<b>Sherman</b>	Philip	participant	Ontario	Canada	Scientific Director		CIHR Institute of Nutrition, Metabolism and Diabetes
<b>Sioui</b>	Konrad	participant, speaker		Canada	Wendake Grand Chief		
<b>Star</b>	Leona	participant	Manitoba	Canada	Research Associate		Nanaandawewigamig , First Nations Health and Social Secretariat of Manitoba
<b>Stirbys</b>	Cynthia	participant		Canada	Associate Director	SFU	CIHR Institute of Aboriginal Peoples' Health
<b>Tano</b>	Merv	participant, speaker	Colorado	United States	President		International Institute for Indigenous Resource Management
<b>Ticknor</b>	Jann	participant	Saskatchewan	Canada	Coordinator, Saskatchewan Indigenous Strategy on HIV and AIDS		All Nations Hope Network
<b>Vides</b>	Eduardo	participant	Ontario	Canada	Senior Health Policy Advisor	Health Sector	Métis National Council
<b>Whitecloud</b>	Katherine	participant	Manitoba	Canada			