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New (and Old) Issues of Health Research Ethics with Aboriginal Peoples

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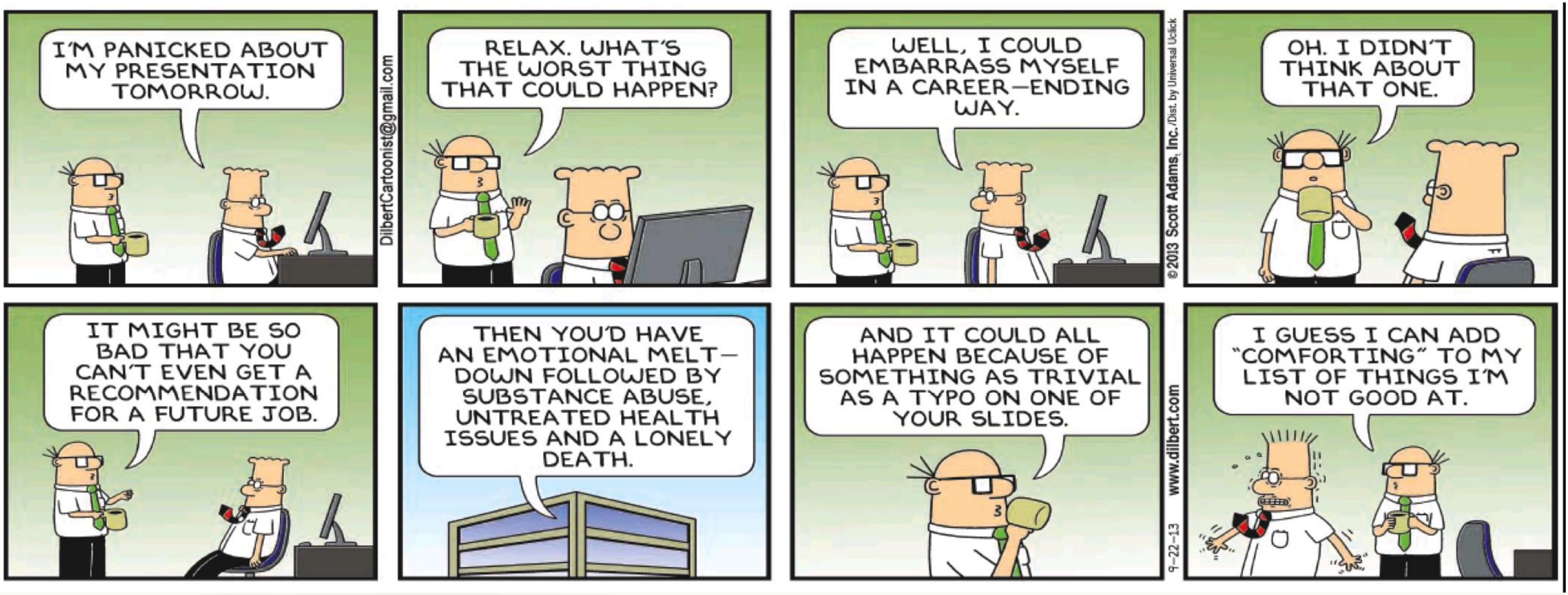
Declaration of Conflict of Interest

I have no conflict of interest to declare.

I have no affiliation, honoraria or monetary support from an industry source.

Declaration of Limit of Comfort



Emerging Issues in Aboriginal Health Research Ethics

1: Secondary use of health data with Indigenous identifiers

2: Data ownership / project ownership: Obligations of researchers and agencies

3: Hunger Research in Residential Schools: Reconciliation

Secondary Use of Health Data With Indigenous Identifiers

First, let me state that perhaps the number one ethical issue here is not how this data is used or should be used, but the fact that there is so little of it. The existence of indigenous identifiers on health databases is incomplete to say the least. Indigeneity and its correlates are predictors of health inequities in many areas. Further, collection of health data with indigenous status identifiers would greatly facilitate the development and monitoring of programs designed to reduce health inequities experienced by First Nations, Inuit and Metis peoples. Is it ethical not to collect such data?

Where substantial data sets are collected, they are mostly held by provincial health agencies. And yet the TCPS states that consultation with Aboriginal communities should be carried out. How can this be accomplished?

Secondary Use of Health Data With Indigenous Identifiers

As the IAPH Scientific Director, I have been asked a number of times how to consult or engage with Aboriginal communities in studies such as the secondary analysis of health data.

An example could be the following: regional/geographical trends in service uptake or delivery directly concerning First Nation, Metis and Inuit people, based on administrative data. Aboriginal people could be one of several subgroups of interest.

The inclusion of Aboriginal people and the associated subgroup analysis is a potential strength of such studies and very much needed given the paucity of data concerning the health of Aboriginal peoples, but meeting the Tri-Council guidelines has sometimes been problematic for researchers.

The TCPS-2 does not require that researchers seek consent from individuals for the secondary use of non-identifiable information (article 5.5, p. 63), however if the data or biological materials can be linked back to the individual either directly or indirectly through linking with another dataset, then researchers must seek consent (TCPS2, chap. 5 & 12).

Secondary Use of Health Data With Indigenous Identifiers

In the case of research involving Aboriginal people, ethics boards need to understand these requirements in the context of the special provisions outlined in TCPS2 chap. 9 – Research Involving First Nations, Inuit & Metis Peoples. That is, if the data or biological materials being used are identifiable, then of course the requirements of TCPS2 for re-consent would apply.

But even if the data for secondary use is non-identifiable, I think most ethics committees would view such secondary data analysis as fitting at least criterion (d) of Section 9.1, and therefore requiring engagement with the relevant community. This may not require individual level re-consent, which could be complicated, costly and time consuming, but some level of community engagement would be respectful and necessary.

Secondary Use of Health Data With Indigenous Identifiers

An appropriate form of engagement for this type of research would be to form an Aboriginal advisory group, inclusive of people in the region(s) relevant to the group whose data is being analyzed. The advisory group could include Elders and community health workers.

If, for example, the aim of the Aboriginal sub-group analysis were to compare regions or geographic zones, it would seem important to include Aboriginal people representing those zones in the advisory group.

Researchers are nevertheless concerned that having to form an advisory group might dissuade them from studying such subgroups at all, which would inhibit Aboriginal health research.

In my opinion, there is more harm done by unduly excluding Aboriginal participants from research; such exclusion would in fact be unethical.
I don’t believe it is the intention of either Tri-Council or CIHR to limit research to non-Aboriginal people.

Secondary Use of Health Data With Indigenous Identifiers

Quite the contrary, ethics policies of this sort should be seen as enabling frameworks that help researchers to better structure their approach and relationships with First Nations, Inuit and Metis communities. These documents were developed in close collaboration with community members and represent established best practices for building research partnerships based on mutual respect.

In fact, the ethics policies are really just a way to formalize what researchers should be doing anyway if they want to ensure quality data and relevant research.

Some involvement of Aboriginal Peoples in secondary data analysis is essential and more of it is needed.

Data Ownership / Project Ownership: Obligations of Researchers and Agencies

By now it is well established that data obtained in a research study belong to the community. The AFN and its affiliate organization FNIGC have established and trademarked the term OCAP. Other indigenous groups have established similar considerations of data ownership and control.

By the commonly accepted principles of community-based research, researchers have an obligation to involve indigenous communities in the planning and design of research projects, the interpretation of data, and the dissemination of research findings.

But what obligation does the researcher have beyond the study? What obligation does the funding agency have? What about the data owner? There are still unresolved issues and undefined responsibilities.

Data Ownership / Project Ownership: Obligations of Researchers and Agencies

For Discussion:

What are the obligations of the researcher to continue to work with the community?

What obligation does the funding agency have?

What about the data owner(s)?

Pathways to Health Equity for Aboriginal Peoples

Pathways goal is to develop a better understanding on how to implement and scale up interventions and programs that will address Aboriginal health inequities in four specific exemplar areas – suicide, diabesity, tuberculosis, and oral health.

Specific goals are:

- to overcome implementation challenges;
- to scale up interventions across a range of settings; and
- to strengthen systems to improve health outcomes while reducing disparities across populations

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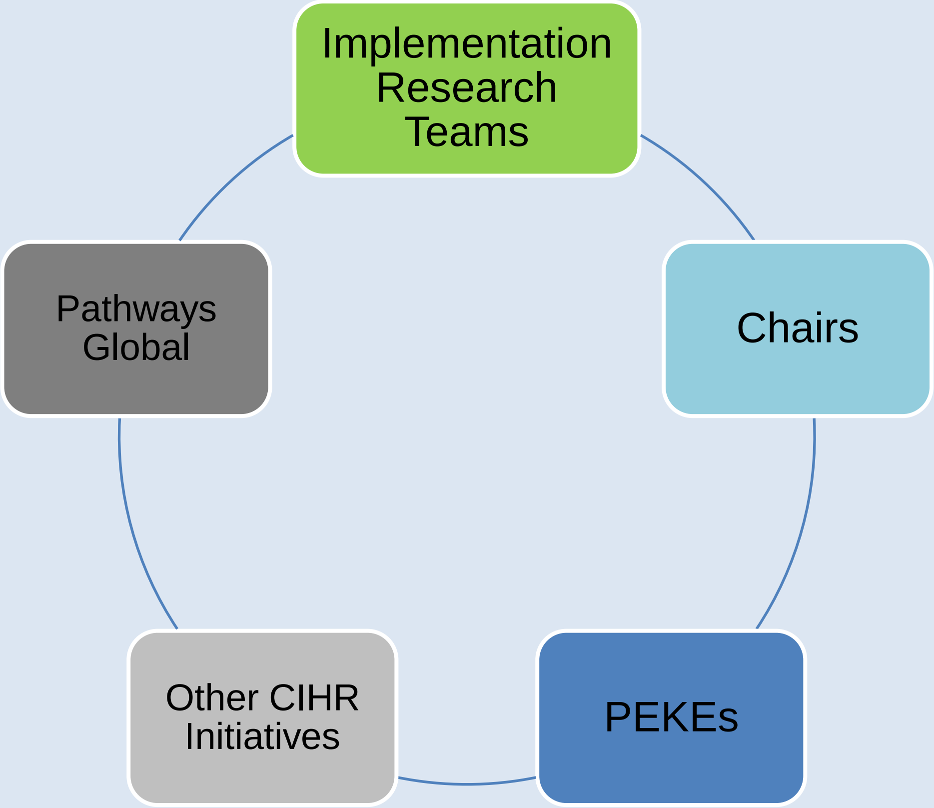
Pathways to Health Equity for Aboriginal Peoples



Implementation Research Teams

Chairs

PEKEs

Other CIHR Initiatives

Pathways Global

Partners for Engagement and Knowledge Exchange (PEKEs)

Support communities, translate knowledge, facilitate implementation research teams, interact with chairs

Leverage the strengths of National Aboriginal Organizations

Health Equity for Aboriginal Peoples: What informs our vision?

Pathways is grounded in the perspective of “two-eyed seeing”, as put forward by Mi’kmaq Elder Albert Marshall.

To see from one eye with the strengths of Indigenous ways of knowing

And to see from the other eye with the strengths of Western ways of knowing

and to use both of these eyes together.

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Old and Unresolved Issues: A Time for Truth and Reconciliation

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Canada’s Residential Schools: 1876-1996

For more than 100 years, Canada’s residential schools systematically undermined Aboriginal culture and disrupted generations of families and consequently contributed to a general loss of language and culture in subsequent generations.

From the 1876 Indian Act until the closing of the last residential school in 1996, 150,000 Aboriginal children, including Status Indian, Métis, and Inuit, were placed in residential schools across Canada.

Today, more than 80,000 residential school survivors remain in Aboriginal communities.

For the first time in decades, survivors are sharing the impact of their experiences with their families, their communities, and with other Canadians (Truth and Reconciliation Commission of Canada).

www.trc.ca/

Hunger Research in Residential Schools

Ian Mosby (University of Guelph). Nutrition Research and Human Biomedical Experimentation in Aboriginal Communities and Residential Schools. 1942-1952.

In the residential schools of the 30s and 40s, malnutrition was a serious issue. This was bad enough, but instead doctors working for Indian Affairs decided that they had an ideal population cohort to carry out experiments on nutrition. 1300 First Nations children at 6 residential schools were the subjects of nutrition experiments.

Many dental services were withdrawn from participating schools during that time. Gum health was an important measuring tool for scientists and they didn't want treatments on children's teeth distorting results.

Hunger Research in Residential Schools

Ian Mosby. Nutrition Research and Human Biomedical Experimentation in Aboriginal Communities and Residential Schools. 1942-1952.

At one school, children were divided into one group that received vitamin, iron and iodine supplements and one that didn't. At another school, levels of vitamin B1 were depressed to create a baseline before levels were boosted. A special enriched flour that couldn't legally be sold elsewhere in Canada was fed to children at another school. And one school was allowed none of these supplements.

Hunger Research in Residential Schools

Ian Mosby. Nutrition Research and Human Biomedical Experimentation in Aboriginal Communities and Residential Schools. 1942-1952.

The scientists conducting these experiments knew from the beginning that the real problem and the cause of malnutrition was underfunding.

Instead of recommending an increase in support, the researchers decided that isolated, dependent, hungry people would be ideal subjects for tests on the effects of different diets.

Ian Mosby's study can be found at
http://muse.jhu.edu/journals/histoire_sociale_social_history/v046/46.91.mosby.html

Redressing the Past: Moving Forward

Shawn A-in-chut Atleo, National Chief of the Assembly of First Nations (July 2013):

We can't change the past but we must commit to change the present and work together to create a better, brighter and just future.

Lloyd Sherman King – December 28, 1915 – April 14, 2006

Those Who Forget The Past
Have No Future

Institute of Aboriginal Peoples' Health
Simon Fraser University

Thank you

Miigwech

Bessie (King) Tobicoe, Frank King & baby Lloyd S King (1916)

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