Research as Noojimo Mikana: Creating Pathways to Culturally Safe Care for Indigenous People

Nov. 15th, 2017
Dr. Carrie Bourassa, Scientific Director, Institute of Aboriginal Peoples’ Health
Chair, Indigenous & Northern Health, Health Sciences North Research Institute

Discoveries for life / Découvertes pour la vie
Research as Noojimo Mikana: Creating Pathways to Culturally Safe Care for Indigenous People

Dr. Carrie Bourassa, IAPH

Brisbane, Australia
Nov. 15th, 2017
I would first like to take the opportunity to acknowledge that we are in the Traditional territory of the Turrbal and Jagera peoples.

Wisdom Water (community knowledge) is at the centre of research and the Hunter-Gatherer has a responsibility to act in an ethical way and undertake research by, with and at the direction of the community.
“We had our own teachings, our own education system – teaching children that way of life was taught by grandparents and extended families; they were taught how to view and respect the land and everything in Creation. Through that the young people were taught how to live, what the Creator’s laws were, what were the natural laws, what were these First Nations’ laws … the teachings revolved around a way of life that was based on their values.” ~ Elder Peter Waskahat, Saskatchewan (Treaty Elders of Saskatchewan, 2000).
Research as Exploitation

- “helicopter research” that often further marginalized Indigenous communities
- Experimentation on Indigenous peoples (ie. Nutrition and human biomedical experiments in residential schools between 1942-1952 documented by Dr. Ian Mosby¹)
- Research conducted without consent including biological samples obtained and removed from communities without consent (ie. Nuu-chah-nulth First Nations community members on Vancouver Island in 2005²)
- Traditional knowledge shared by Knowledge Keepers, Elders, Healers is appropriated without the knowledge or consent of the community (ie. To develop pharmaceutical products)
- The research is not beneficial to the community and the community is not involved in the design, analysis and are virtually “subjects” of the research.
Research as Exploitation

- Some common grievances:
  - The majority of research projects are initiated, paid for and carried out by non-Aboriginal people from universities, government and industry;
  - Some researchers have essentially pre-empted meaningful community involvement by presenting completed research designs, often already funded, for community approval rather than collaborating from the start;
  - Governments gather administrative and other data on First Nations without their knowledge or consent;
  - Governments and researchers analyze, interpret, and report First Nations data without consent, approval, review, or input by First Nations representatives;
  - Research funding is largely controlled by a few external agents and is generally not accessible to community groups and First Nations organizations;
  - Human remains and cultural property have been taken for storage, display in museums, or sale (NAHO, 2004).
Ethical Research: Indigenous Principles and Concepts

- **Concepts of:**
  - Reciprocity
  - The collective
  - Building relationships
  - Giving back
  - Holism
  - Responsibility
  - Respect
- **Processes:**
  - Capacity Building
  - Community Control
  - Community Engagement
  - Collaboration
  - Cultural Responsiveness
Indigenous KT?

• But what is Indigenous KT?
• Sharing what we know about living a good life
• A dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of people
• “reduce the know-do gap”
• But what is it really for Indigenous people?
• It’s about exactly what we have been talking about ... it’s about reciprocity, relevance, respect, benefit to community, it is about what works for them, by them
- “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, Chpt. 5, 1996).
Ethical Research as Self-Determination

• Originally was “OCA” coined during a brainstorming session of the National Steering Committee of the First Nations Regional Longitudinal Health Survey (RHS) in 1998 (NAHO, 2007).

• Can be linked to poor history of research with First Nations and Métis communities.

• Ownership, Control, Access, Possession (OCAP) is self-determination applied to research (NAHO, 2004).

• It is a political response to colonial approaches to research and information management. (NAHO, 2004).

• **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 people 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.
Ethical Research as Self-Determination

• **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 breech or misuse. This is particularly important when trust is lacking between the owner and possessor.
“First Nations’ claim to ownership of their own data is not some strange new aberration. On the authority of their own institutions and laws, governments and academics have long possessed and owned data without really thinking twice about it. OCAP brings the illegitimate owners into the spotlight. Those who most strongly reject the notion of data ownership tend to have control or possession of considerable volumes of it” (NAHO, 2004).
Ethical Research as Self-Determination

- OCAP asserts that First Nations governance and self-government imply jurisdiction and control over a full range of institutions and processes, including research and information (NAHO, 2004).

- OCAP asserts First Nations’ authority to control their own research and information. Information can produce prosperity and can serve as the bedrock for policy and planning. OCAP is about enhancing First Nations’ resources. It is about *nation building* (NAHO, 2004).

- Historically, most research involving Aboriginal peoples has been conducted in rural or reserve settings (Bartlett, et al. 2007;). However, migration to cities from rural towns, villages and reserves is increasing in Canada (Statistics Canada, 2008).

- While OCAP could be applicable to a variety of communities, some have argued that it is not as applicable to urban, off-reserve and Métis communities. Thus, other models have been used and examined.
Ethical Research Research Guidelines

- CIHR’s Guidelines for Health Research Involving Aboriginal People were released in 2007 after a national consultation with First Nations, Inuit and Métis communities, researchers and institutions (CIHR, 2007).
- CIHR requires that a research agreement be signed with an Aboriginal community within one year of CIHR funding.
- Guidelines were more generic but had similar themes that are seen in the OCAP principles (ie. Respect jurisdiction, research benefit the community).
- Became redundant when TCPS 2nd edition were finalized in fall 2010.
- “The CIHR Guidelines for Health Research Involving Aboriginal People are no longer CIHR funding policy. Health research involving First Nations, Inuit and Metis people in Canada is henceforth governed by the provisions outlined in Chapter 9 of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS).” (CIHR, 2011)
Ethical Research Research Guidelines

- Tri-Council Policy Secretariat, 2nd Edition (TCPS 2)

- Indigenous Research Ethics Boards (ie. Mi’kmaq Confederacy Ethics Review Committee; Mi’kmaw Ethics Watch; Manitoulin Island Research Ethics Committee)

- Some communities have developed guidelines for ethical research (ie. Manitoba First Nations Education Resource Centre Inc. developed “Guidelines for Ethical Research in Manitoba First Nations” in 2014)
Current Community-based Research Priorities

- Research priorities are established by the community directly or sometimes through community research advisory boards.

- Indigenous Community-based Health Research Lab (Morning Star Lodge) – guided by an Elder (http://www.indigenoushealthlab.com/) - Canada Foundation for Innovation funded (community lab and student training lab)

- 11 funded grants – all have Indigenous Community Research Advisory Boards led by Elders

- Research agreements with all Indigenous partners

- Full engagement, capacity building, direction from communities


- Mentorship of community members, undergraduate and graduate students is a priority

- We don’t have a hierarchy in the lab – everyone is a mentor – reciprocal learning

- Elders and Community partners are central to training and mentorship (academic training is only one aspect of one’s learning)

- KT is innovative and beneficial – could be a training module; video; language app

- http://www.indigenoushealthlab.com/
Research as Reconciliation?

- What does this look like?

  The TRC says the following about reconciliation:
  
  “Reconciliation must become a way of life. It will take many years to repair damaged trust and relationships in Aboriginal communities and between Aboriginal and non-Aboriginal peoples. Not only does reconciliation require apologies, reparations, the relearning of Canada’s history and public commemoration but it also needs real social, political and economic change”. (TRC, 2015:19)

They also argue that “research is vital to reconciliation [and] it provides insights and practical examples of why and how educating Canadians about the diverse concepts, principles and practices of reconciliation contributes to healing and transformative social change” (TRC, 2015: 293).
The TRC made specific recommendations in relation to Indigenous health:

19. We call upon the federal government in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long-term trends. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services.

22. We call upon those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients.

23. We call upon all levels of government to:
   • i. Increase the number of Aboriginal professionals working in the health care field.
   • ii. Ensure the retention of Aboriginal health care providers in Aboriginal communities.
   • iii. Provide cultural competency training for all health care professionals.
The State of Indigenous Peoples’ Health

- Aboriginal population in Canada is 3.8% (an increase from 3.3% in 2001)
- Aboriginal population grew by 45% between 1996 and 2006 - almost 6 times faster than the general Canadian population
- The Aboriginal population is predominant in Ontario and the Western provinces where 8 in 10 Aboriginal people reside
- First Nations people continue to suffer from high rates of chronic and infectious disease and higher mortality and infant mortality rates compared to the general Canadian population
- CVD, Diabetes, Obesity, Cancer, Stroke, Suicide, Motor Vehicle Accidents and Homicide are major causes of death among Aboriginal populations
- The **life expectancy of First Nations** peoples was estimated at 68.9 years for males and 76.6 years for females, reflecting differences of 7.4 and 5.2, respectively, from the Canadian population’s life expectancies.
The State of Indigenous Peoples’ Health

- Preventable deaths due to **circulatory diseases (23% of all deaths) and injury (22% of all deaths)** account for a near staggering 50% of all deaths.

- For First Nations ages 1 to 44, the most common cause of death was **injury and poisoning. The primary cause of death** for children less than 10 years was classified as unintentional (accidents).

- **Suicide rates for Aboriginal youth range** from 5-7 times higher than the national average.

- The potential **years of life lost from injury alone was more than all other** causes of death and was almost 3.5 times that of the general Canadian population. (Health Canada, 2008)
The State of Indigenous Peoples’ Health - Women

- The mortality rate due to violence for Aboriginal women is 3X the rate experienced by all other Canadian women.
- Aboriginal women with status under the Indian Act & who are between the ages of 25 & 44 are 5X more likely to experience a violent death than other Canadian women in the same age category (Amnesty Int’l, 2004)
- Six in 10 (59%) Aboriginal female spousal violence victims reported injury, while about 4 in 10 non-Aboriginal female victims were injured (41%) (StatsCan, 2013).
  - Status First Nations women are five times as likely as non-Aboriginal women to be non-participants in the labour force (Statistics Canada, 2001)
  - Aboriginal women have lower incomes, less formal education, live in poorer housing, have lower health status, & have a greater chance of becoming lone parents.
  - 43% of Aboriginal women live in poverty*

- Does History Matter?
- As the Canadian Research Institute for the Advancement of Women (CRIAW) notes:
  - “Racism and sexism combine to produce more economic inequalities for racialized women than experienced by either white women or racialized men” (2002).

*Canadian Research Institute for the Advancement of Women, 2002.
Root Causes of Ill Health Among Indigenous People

- Disparities in health exist on the basis of race in Canada (Lasser et al, 2006). Racism, oppression, historical legacies and government polices continue to perpetuate the ongoing state of Indigenous Peoples’ health inequities in many Indigenous communities (Virginia Department of Health, 2013).

- Indigenous Peoples carry an inordinate burden of health issues and suffer the worst health of any group in Canada. Beyond that, Indigenous people experience the poorest living conditions, inequitable access to education, food, employment and healthcare/health services in a country that reliably ranks in the top ten on the United Nations human development index (Diffey and Lavallee, 2016; Allan & Smylie, 2015; Reading & Wien, 2009).

- Inequitable access leads to the worst health outcomes (Aboriginal Health Advisory Committee, 2012; Reading & Wien, 2009), but most importantly racism has been identified as the major factor in creating and reinforcing these disparities (Diffey and Lavallee, 2016; Allan & Smylie, 2015; Hart & Lavallee, 2015; Loppie, Reading, & de Leeuw, 2014).

- This racism is rooted in our colonial history and the processes that have – and continue to – disconnect Indigenous communities from their lands, languages, and cultures (Diffey and Lavallee, 2016; King, Smith, & Gracey, 2009; Commission on Social Determinants of Health, 2007).

- However, Indigenous people are resilient, we do have greater capacity to undertake research and we have far more community engagement and direction than ever before.

- One of the immediate priorities of the institute is to engage Indigenous grassroots communities to ensure the priorities identified truly do reflect community priorities. Communities are also very keen to see strengths and asset based solutions and that included research initiatives.
IAPH Strategic Focus & Priorities

The IAPH will provide leadership to a national research agenda to create and translate new knowledge to improve the health of Aboriginal, or Indigenous, Peoples (i.e., First Nations, Métis and Inuit). Such an agenda will be aligned with the CIHR Health Research Roadmap II and, in particular, with Research Priority B: Health and Wellness for Aboriginal Peoples.

- The Institute will focus its strategic agenda and initiatives on **three** strategic directives. These directives, with related initiatives, are as follows:

  1. To propel First Nations, Inuit and Métis Peoples and communities to drive First Nations, Inuit and Métis health research and knowledge translation
  2. Mentor and train the next generation of First Nations, Inuit and Métis researchers.
  3. Incorporate concepts of Indigenous wellness and Ways of Knowing into all CIHR initiatives.
  4. Stimulate and support collaborative networks of researchers, policy makers, service providers and First Nations, Inuit and Métis Peoples and communities to translate knowledge to improve the health of Indigenous populations.
IAPH Strategic Focus & Priorities

To transform First Nations, Inuit and Métis health using Indigenous Ways of Knowing, and the guiding principle of reciprocal learning

2

• Design research funding opportunities that ensure First Nations, Inuit and Métis Peoples are an integral part of the entire research process.

a

• Infuse Indigenous Ways of Knowing and reciprocal learning into the research process in order to catalyze respect for Indigenous knowledge, values and cultures.

b

• Advocate for the use of Indigenous Ways of Knowing and the reciprocal learning to influence research priorities and to determine interventions useful to First Nations, Inuit and Métis Peoples.

c
IAPH Strategic Focus & Priorities

3. To advance beyond acknowledged notions of health equity and give primacy to wellness, strength and resilience of First Nations, Inuit and Métis Peoples

   a. Collaborate with First Nations, Inuit and Métis Peoples to convey and advance concepts of wellness as standards for policy and practice to better the health of all Canadians.

   b. Collaborate with international bodies to foster the integration of wellness into Indigenous health research and knowledge translation.

   c. Work with researchers and policy makers to identify indicators to measure and monitor wellness.
To realize these three strategic directives, the IAPH will invest in CIHR initiatives and other activities of potential interest. Examples include the CIHR Roadmap Accelerated Fund (RAF) initiatives (i.e., the Pathways to Health Equity for Aboriginal Peoples that started in 2013-14, the Healthy Life Trajectories Initiative that started in 2015-16, and the Canadian Arm of the Healthy Life Trajectories Initiative, which will begin in 2017-18); the CIHR Indigenous Mentorship Network Program; and the New Iterative Peer-Review Process for Indigenous Health Research Applications.

**Goals** - The goals of the IAPH strategic development activities are three-fold:
1. To support CIHR in increasing its investments in Indigenous health research to a minimum of 4.6% of CIHR’s annual budget;
2. To create new knowledge pertaining to Indigenous health;
3. To translate that knowledge to improve the health of First Nations, Inuit and Métis Peoples.
How can you translate knowledge as we outline in point 3 if Indigenous communities are not directing the research? We must take our responsibility as Hunter-Gatherers seriously and privilege Wisdom Water, privilege Indigenous communities and create the ethical space to ensure that it is Indigenous communities driving the research agenda – full stop. Let us listen more, speak less.

Megweetch/thank you, All My Relations
References and Good Reading

References and Good Reading


1http://www.ianmosby.ca/administering-colonial-science/


3Report of the Indigenous Peoples’ Health Research Centre to the Institute of Aboriginal Peoples’ Health, the Canadian Institutes of Health Research Willie Ermine, M.Ed, Raven Sinclair, PhD Candidate, Madisun Browne, LLB Indigenous Peoples’ Health Research Centre Saskatoon, SK ©Indigenous Peoples’ Health Research Centre, March 2005
Megweetch ...

- Special thanks to my Kookum Elder Betty McKenna, Dot Beaucage Kennedy and Elder Juliette St. Denis, our Elders who provide guidance to our labs, projects and student researchers.

Thank you also to the NHMRC and Lowitja Institute Planning Committee for inviting me and for volunteering to make this conference such a huge success!
If we truly want to live as one we first have to create a world that is good for all

~ ArchDuke White Privilege Explained

Dr. Carrie Bourassa
Scientific Director,
IAPH

Email: cbourassa@cihr-irsc.gc.ca
Phone: 306-519-1745