



## CAHS Major Forum on Indigenous Health Summary Paper Arising from Forum November 16, 2016

### Re-imagining Relationships

*“The inequities in the health of First Nations, Inuit and Métis are well-known and long-standing. They are built on Canada’s colonial past, and fed by the on-going resistance to reconcile with the injustices of the past and the present. Reconciliation as a pathway to Indigenous health equity requires relationship building between Indigenous and non-Indigenous people, as well as fostering better understanding of each other’s worldviews and ways of knowing”*

Malcolm King, Keynote Speaker, CAHS Forum

#### Overview

On September 15, 2016, the Canadian Academy of Health Science (CAHS), whose members consist of the leading voices in health research in Canada, focused its annual major forum on Indigenous health. The day was aimed at identifying key issues facing surrounding Indigenous health today and developing insights for how to move the conversation and research agenda away from a problem-based discourse towards solution-oriented research.

The Forum was opened by Mrs Amelia Tekwatonti McGregor, Bear Clan, Kahnawake Mohawk Territory. Context for the day was offered by two Keynote Speakers, Malcolm King, Scientific Director, CIH Institute of Aboriginal Peoples' Health, and Linda Tuhiwai Smith, University of Waikato, New Zealand.

An additional 10 scholars<sup>1</sup> offered highlights of their work and discussed key questions in three panels: the first on *Reconciliation and Relationships*, and two on *Health Solutions for the Future: Promising Practices*. The day was chaired by John O’Neill and Jeff Reading, both of Simon Fraser University. Topics included the historical roots of the Truth and Reconciliation Commission, ethical issues, respectful genetics research with Indigenous communities, an arts-based approach to healing in HIV/AIDS and Aboriginal Women, mental health in northern communities, funding arrangements and jurisdictional disparities, a health promotion project to prevent diabetes in Kanawake, and Northern and Inuit perspectives on environmental change.

At the end of the day, Academy members were invited to participate in a group process to identify the most significant themes of the day and to propose ideas for next steps for the CAHS. Margo Greenwood, Vice President of Aboriginal Health for the Northern Health Authority and Academic Lead of the National Collaborating Centre for Aboriginal Health, provided closing remarks, focused on what truly respectful partnership looks like.

#### Background and the Need

Deep-rooted health inequities among Indigenous peoples are widely recognized as among the most significant issues in Canadian life. The gap in life expectancy between Indigenous and other Canadians is seven years; Indigenous people are more likely than other Canadians to have hearing, sight and speech disabilities; and Indigenous people have significantly higher rates of diabetes, HIV and other diseases than the rest of Canadians.

The social determinants of poor health are well understood – access to health services, income, education, employment, living conditions, social support. Among Indigenous peoples, racism, culture loss, disconnection from ancestral lands and identity, and stigma further compound these inequities. Identity itself is a health determinant for Indigenous people. While health researchers and scientists have been working with Indigenous communities for decades, effective solutions have not been successfully shared, understood or integrated broadly.

There is a convergent moment for transformative action on Indigenous health. The federal government has declared Indigenous health a priority. The findings of the Truth and Reconciliation Commission included 94 calls to action, nine of which were directly health related, and 70 relate to social determinants of health. Organizations such as CIHR's Institute of Aboriginal People's Health and BC's First Nations Health Authority are making profound progress in generating knowledge and action about improving the health of First Nations, Inuit and Métis people, by bringing together scientists, policymakers and indigenous communities and leaders.

### **Self-Determination as the Key Success Factor in Change**

There were three prevailing themes from the Forum:

- 1) CAHS is uniquely positioned and empowered to articulate and facilitate the kinds of shifts in knowledge development and translation that are needed to transform the health of indigenous peoples in Canada. CAHS needs to play a role in providing policy and law-makers with the evidence and recommendations to move toward resolving health inequity.
- 2) Appreciation and recognition that there are a multitude of examples of successful health promotion and service improvement and interventions in Indigenous communities that can be learned from and shared.
- 3) A complex tension about the fact that typical scientific approaches to “spread and scale” are not directly applicable to Indigenous health, since the key “success” factors for improving indigenous health are self-governance, local decision-making, community engagement and contextualized approaches. Transforming Indigenous health requires an inversion of the “expert” scientific model to a truly collaborative approach that is built around self-determination, community need and cultural ways of knowing and ethics.

The following example illustrates the tension inherent in the last two points. Throughout the day, people mentioned the relationship between a colonized diet and diabetes, and a few suggested that solutions aimed at decolonizing diets would be useful. Similarly, people noted the successes of the Kahnawake Schools Diabetes prevention project, which engaged the community in creating and leading a multi-faceted health promotion project that included both exercise and diet, and suggested that this could be replicated elsewhere.

While it is incontrovertible that there is a relationship between diet/exercise and diabetes, every presenter emphasized that it is not only the evidence about diet and exercise that matters in an Indigenous context, but equally important, how the researchers/health promoters engage the community in interpreting scientific knowledge and co-creating solutions. It is not the diet itself alone,

but even more important, it is the act of self-determining the health promotion actions from inside the community that makes a difference to success.

This shift away from isolatable, scalable factors is an inversion of the usual scientific role. The role of the scientist becomes partner and collaborator, not expert. This can be difficult to grasp; one commenter in the final day's discussion suggested, for example, that a promising solution was to "teach people to revert to the ways of their ancestors." This phrasing picks up on the notion of respecting Indigenous knowledge, but reinforces a concept of the scientist as paternalistic expert. This phrasing points to the need to let go of the notion of the scientist as a detached expert, one who can isolate factors that will work across multiple contexts or in different sites and then hold the privileged role of teacher – to reframing researchers as relationship builders and members of a web-like community.

### **Shifting Conceptualization of Knowledge**

Every presenter underlined the fundamental principle that researchers working in Indigenous health need to integrate Aboriginal ways of knowing into their work as fully as they honour other epistemologies. This knowledge is embedded in Indigenous stories, sacred practices, culture and art, and can include both "what we need to live" and "what we can do to destroy ourselves" (Tuhiwai Smith). Researchers have an ethical obligation to recognize that research can reinforce the very forms of colonization and racism that contribute to health inequity (Brant Castellano). Even bio-scientists collecting genetic material need to think of biological materials such as DNA samples as being "on loan" to researchers (Hegele). Research processes must recognize that the act of research itself, not the results of a study, can be harmful or healing, and should be crafted accordingly (Loppie). Research should be focused on wellness and strength, and engaging people in moving toward that strength (Loppie, King, McComber and Macauley).

The prevailing theme from each of the scholars working in Indigenous health who presented at the Forum was that it is both knowledge about specific health conditions AND the engagement of the community itself in a self-determined solution that makes a difference. In a context where the intergenerational effects of racism, colonization and external "solutions" imposed on communities are in themselves social determinants of poor health and inequity, science needs to shift its "expert" stance to one of collaboration. Engagement is not only a way of sharing knowledge, but part of the scientific solution itself.

### **Self-determination in research practice and governance**

This approach requires people to reframe what "counts as evidence" (Tuhiwai Smith), and to recognize the reciprocal relationship between the researcher and the community, where "indigenous individuals are analyzing researchers too" (Tuhiwai Smith). This requires both a shift in governance and a shift in research practices.

Research practices that facilitate sustainable action and change include community-developed and facilitated solutions to health promotion (McComber and Macauley), research as part of a continuous conversation with a community (Hegele), arts-informed and visionary narratives (Loppie), and other forms of participatory research (Kirmayer). This shifting role for the researcher and for knowledge needs to be integrated into the training environment for the current and next generation of researchers (Kirmayer).

These research practices need to be fostered in parallel with structures that enable self-governance and mutually respectful relationships between Indigenous and non-Indigenous people.

One highly promising example of this kind of collaborative relationship is the Inuit Circumpolar Council, which is one of several Indigenous organizations that have created partnerships with the Northern Contaminants Program, to conduct and inform scientific research to combat environmental change related to contaminants in the Arctic (Ayotte).

This kind of meaningful partnership may be a useful framework to apply across all health topics. Currently, only two provinces (BC and Ontario) recognize the need for Indigenous people to have a say in health authorities' decision making, and there is fragmentation across all jurisdictions (Lavoie). The First Nations Health Authority in British Columbia is the most promising, far-reaching example of a governance structure based on the principle of "nothing for us without us" (Gallagher).

The First Nations Health Authority is a tripartite, collaborative relationship between BC First Nations, the Province of BC and the Government of Canada with a unique self-governing structure with political representation and advocacy through the First Nations Health Council and technical support and capacity development from the FN Health Directors Association. The structure itself and the focus of its work is aimed at supporting individuals, families and communities to be self-determining, grounded in core concepts of cultural competency, cultural humility and cultural safety. The vision is a "mutual, collaborative relationship between First Nations people and their care providers."

### **Participants' Perspectives**

At the end of the Forum, the table discussions indicated that CAHS members believed that there is an ethical imperative for CAHS to take on a role in creating the research and knowledge translation models that will help transform inequities in indigenous health. At the same time, perspectives within the group pointed to the tension that is generated by scientific approaches which position researchers as experts with "participants" or "subjects, and offer solutions from the outside. Projects must be carefully constructed so they do not further contribute to colonization.

In her presentation on ethical issues, Brant Castellano emphasized that moving to a more mutually respectful relationship requires a lot of education and building of shared understanding between Indigenous and non-Indigenous people. Many of the commenters in the final group discussion of the day picked up on this theme, emphasizing that *Scientists must develop a more open mind about the place and value of indigenous knowledge/indigenous ways of knowing*. Commenters underline the need to shift assumptions about what counts as evidence, to interlace spirituality, culture and indigenous views of health with our other research lenses, rethinking the way researchers frame issues and engage with communities, and bring "cultural humility" to the work.

In this rethinking of the approach to science, participants underlined the need to learn from the "7<sup>th</sup> generation principle" and to combat reactive, short-term initiatives. One main need is to examine and change the systemic and structural barriers to using Indigenous methodologies – e.g, measuring success – and to find a different starting point than the traditional scientific approach of looking at existing knowledge.

Across all of these comments, the underlying message seemed to be that a movement to transform researchers and ways of researching, as much as transforming the health of people in indigenous communities, is needed.

This movement needs to be built on self-determination, a platform of “*Nothing about us without us*” – all indigenous health research and improvement efforts must be done in partnership with the indigenous community. The work cannot be framed as “we are the experts here to fix you,” but as a bidirectional, facilitated approach self-determined solutions, focused on strengths, not deficits. Building networks is as important as generating evidence.

## **Conclusions and Next Steps**

CAHS’ usual approach to important health issues is to undertake a major assessment that consolidates knowledge and makes concrete recommendations for change. In the case of Indigenous Health, , the transformation that needs to take place is as much about how science and knowledge are framed, funded, planned and conducted as they are about the topics or the content of that research.

The Forum pointed to five overarching themes:

- 1) Self-determination and participative approaches to community wellness research and interventions are an essential part of facilitating sustainable change with Indigenous peoples, and are the essence of moving past the effects of colonization
- 2) Health researchers need to incorporate Indigenous ways of knowing, true collaboration and cultural humility, and a focus on wellness and strength-based approach into their work on Indigenous health
- 3) Success stories are less about the isolatable, scalable factors and more about supporting communities to use knowledge to co-create solutions that work in their own contexts
- 4) We need to transform what counts as evidence and the structural barriers to Indigenous knowledge
- 5) Self-governing structures such as the First Nations Health Authority are the most promising examples of transformative funding, governance and structural approaches to resolving health inequities among Indigenous people

Possible questions for a Major Assessment to build on these five themes are:

1. How can health systems respond to the call to action of the Truth and Reconciliation Commission?
  - How can we create Canadian strategies toward actionable solutions for reducing indigenous health inequities that are based on both health science and indigenous knowledge?
  - How can self-governance and self-determination be built into the health system across all jurisdictions?
2. How can cultural safety and humility be embedded in the healthcare system?
3. What structures would sustain indigenous wellbeing?
  - What is the most appropriate and culturally sensitive way to engage the health research community in these questions?
  - How could the organization of funding better align with active and sustained community participation?
4. What cross-jurisdictional policies could create a more cohesive approach to health, and address systemic and structural racism and inequities?

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## **i List of Speakers**

### *Keynote Speakers:*

Contextualizing the conversation: Why are we where we are in terms of Indigenous health in Canada? Malcolm King, Scientific Director, CIHR Institute of Aboriginal Peoples' Health

Linda Tuhiwai Smith, University of Waikato, New Zealand Health Solutions - What is going on elsewhere?

Panel 1: Reconciliation And Relationships: Framing The Issues

*Introduction & Panel Chair:* John O'Neil, Simon Fraser University

- I. Truth and Reconciliation Commission, Jeff Reading, Simon Fraser University
- II. British Columbia First Nations Health Authority Joseph Gallagher, Chief Executive Officer, Fnha
- III. Ethical Issues Marlene Brant Castellano, Trent University

Panel 2a Health Solutions for the Future: Promising Practices

*Introduction & Panel Chair:* Stewart Harris\*, Western University

- I. Respectful Genetics Research with Indigenous Communities Robert Hegele, Western University
- II. HIV/AIDS and Aboriginal Women, Charlotte Loppie, University of Victoria
- III. Mental Health Laurence J. Kirmayer, McGill University

Panel 2b Health Solutions For The Future: Promising Practices

*Introduction & Panel Chair:* Laurence J. Kirmayer\*, McGill University

- I. Comparison Funding Arrangements in Health Care Delivery Josee Lavoie, University Of Manitoba
- II. Diabetes: Kahnawake Experience Ann Macaulay, McGill University and Alex Mccomber, Kahnawake Schools Diabetes Prevention Project
- III. Environmental Change: Northern & Inuit Perspectives Pierre Ayotte, Université Laval