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INTERNATIONAL REVIEW
OF THE
CANADIAN INSTITUTES OF HEALTH RESEARCH

Expert Review Team Report
for
Institute of Aboriginal Peoples' Health

Submitted by: Dr. Jeff Henderson
Chair, Expert Review Team
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Canadian Institutes of Health Research | Instituts de recherche en santé du Canada

Canada

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Summary

The Institute for Aboriginal Peoples' Health (IAPH), 1 of 13 institutes within the Canadian Institutes for Health Research (CIHR), was launched by the Canadian Parliament with the CIHR Act of 2000, which created CIHR and, with it, the IAPH. The IAPH has arguably the most daunting mandate of all the CIHR institutes. This is because the IAPH does not concern itself with any particular body system or group of systems. Rather, it is charged in essence with addressing the health-related inequities across the entire spectrum of physical, emotional and environmental pathways experienced by individuals and communities of First Nations, Inuit and Métis (FNIM) descent. This mandate is made infinitely more difficult due to the profound physical, social, cultural, linguistic, geographic and environmental diversity represented among these special populations. Add to this the fact that the IAPH was created *de novo*, void of any history or infrastructure (versus, for example, many of the other institutes, which emerged from the legacy of the Medical Research Council of Canada), and the magnitude of the challenge can only begin to be appreciated.

A prescient decision was made to focus on capacity-building and infrastructure development early in the IAPH's history. At the time of its creation, there were few researchers of FNIM descent, and even fewer FNIM communities that were familiar with, trusting of, or equipped to deal with health-related research and researchers. In response, the IAPH conceived of and created the Aboriginal Capacity and Developmental Research Environments (ACADRE) program. A 2005 comprehensive review of the first three years of the ACADRE program concluded in part that "…all ACADREs have made marked progress towards the attainment of the program's overall goals …", and an explicit list of 21 recommendations were made.

This program was revised in response to this review and input from the ACADRE centers and FNIM communities, and in 2007 the Network Environments for Aboriginal Health Research (NEAHR) program was launched. The ACADRE-NEAHR program has been the chief vehicle of the IAPH to address student and faculty development and training, institutional infrastructure, community outreach and engagement, bioethics and knowledge translation. This is why, as the flagship program of the Institute, it is disappointing that there is only one concrete example of one of the other 12 CIHR institutes significantly engaging with one of the ACADRE-NEAHR centers, in this case the Montreal center. The ACADRE-NEAHR program is slated to continue as an important part of IAPH's strategic plan for the next 10 years.

The Expert Review Team (ERT) concludes that the IAPH has achieved much and produced significant and measureable outcomes with respect to increasing both the number of FNIM researchers and, perhaps most importantly, fostering supportive infrastructure and significantly reducing the skepticism and distrust of health research by FNIM communities. Perhaps its most long-ranging achievement thus far is its fostering

of the development of the CIHR Guidelines for Health Research Involving Aboriginal Peoples, an effort which bridged the domains of knowledge translation and bioethics. The Guidelines are now attracting wide attention and being promulgated in local, regional, national and international arenas.

Research gaps identified during the course of our review included attention paid to Aboriginal urban health; social determinants of health, especially for Inuit health; traditional Aboriginal medicine research; and research into the efficacy and effectiveness of the health delivery systems that are charged with providing care to Aboriginals.

For all its successes we find too, however, that the IAPH confronts several very significant challenges in continuing to meet its mandate and advance its duties. Chief among these are issues related to funding and collaboration. On the funding front, historically, the IAPH has been funded at a level proportionate with the FNIM population, or roughly 3.5% of the overall CIHR budget. While at face value this might seem equitable, for all the reasons noted above this is inequitable. The IAPH is being charged with doing more than any other institute, yet it is expected to do so with the smallest of all institute budgets, rivaled only by the Institute for Gender and Health. The IAPH has also experienced a roughly 25% reduction in its strategic grant monies since 2007-2008, the largest decrease of the eight CIHR institutes for which this ERT received reports.

On the collaborative front, there remain many apparent possibilities that the IAPH has yet to benefit from. While conducting admirable outreach, consultation and engagement with FNIM communities, the IAPH has seemingly not yet enjoyed comparable collaboration or partnership from within the CIHR. Only 2 of the 7 institutes available for review by this ERT made any significant mention in their internal assessments of Aboriginal or FNIM populations or the IAPH. As noted above, only one institute outside of the IAPH has apparently partnered with an ACADRE-NEAHR center, a flagship program of the IAPH. Suffice it to say that the greater partnership of the CIHR and its 12 other institutes with the IAPH will be a very important facet of future efforts to improve the health and wellness of Aboriginal populations. So, too, will be current efforts to develop greater partnership with the other two federal health research granting Councils and prominent public health foundations (e.g., Canadian Diabetes Association).

In summary, the ERT finds that the IAPH has performed admirably and has achieved some notable, discrete achievements and outcomes in its relatively brief existence. It has come to embody a best practice with respect the Aboriginal community engagement and outreach, and the ethical conduct of health research with these special populations. However, a much larger commitment needs to be made on the part of the CIHR to both support and extend these efforts. It will take much more than simply the efforts of the IAPH and its affiliate centers and programs to “move the needle” of Aboriginal health and wellness.

Section 1 – Institute mandate

The Institute of Aboriginal Peoples' Health supports health research that addresses the special needs of Aboriginal peoples in Canada. The Institute aims to improve the health of First Nations, Inuit and Métis peoples by:

- Leading a national, advanced research agenda that fosters innovative, community-based and scientifically excellent research
- Asserting Aboriginal understandings of health
- Enhancing knowledge translation and exchange
- Advancing capacity and infrastructure in FNIM communities
- Forging effective partnerships regionally, nationally and internationally

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Section 2 - Status of this area of research in Canada

Numerous commentators spoke to the fact that the establishment of IAPH has profoundly reconfigured the landscape for the conduct of Aboriginal health research in Canada. Particularly noted were broad gains in the quantity of Aboriginal health research conducted; the markedly growing cadre of researchers of First Nations, Inuit and Métis descent; the enhanced profile and respect for Aboriginal health research; and the ways that these efforts have served to diminish skepticism and distrust of health research on the part of Aboriginal peoples and communities. Less documented are clear gains in either numbers of FNIM health research faculty members in colleges and universities, or in discrete improvements in the health status of FNIM populations. However, one interviewee insightfully noted that it has been a centuries-long process to arrive at the current state of Aboriginal health (inequities), and it will certainly take much longer than 10 years, and the concerted efforts of lots of individuals and institutions, to make significant headway in efforts that result in marked improvements in health status for Canada's First Peoples.

Overall impression of the Canadian research landscape in this area

The overall impression is one of a vigorously growing body of Aboriginal health research in Canada with, importantly, more of the research being conducted by Aboriginal people themselves. The stated movement toward supporting more intervention research seems both timely and appropriate, though there remain specific areas where more descriptive research is needed; additional research gaps are noted elsewhere in this report. Critically, there was consensus that the respectful, equitable partnership and collaboration of *both* Aboriginal and non-Aboriginal individuals and institutions is needed now and for the foreseeable future.

Section 3 - Transformative Impacts of the Institute

Numerous interviewees spoke of the clearly transformative impacts of IAPH. In particular, the Institute's capacity-building efforts, initially through ACADRE and now NEAHR, are noted to have rapidly increased both the pool of competitive Aboriginal researchers at high levels, and the breadth and depth of Aboriginal health research being conducted. In addition, community-based work fostered by the Institute is viewed as having reshaped the entire enterprise's meaning and understanding of knowledge translation, a key overarching goal of the Canadian Institutes of Health Research. Finally, the *CIHR Guidelines for Health Research Involving Aboriginal People* is viewed as having transformative effects not only institutionally, but also on regional, national, and international levels.

Overall impression – to what extent has this Institute been transformative?

The IAPH of the Canadian Institutes of Health Research has been transformative beyond what was imagined for a now 10-year new Institute developed from the ground up. The potential for even more significant transformation awaits, which likely hinges on even greater partnership and collaboration, and this is perhaps no more true than with respect to the next 10-year period of existence for this Institute.

Section 4 - Outcomes

Multiple sources of information corroborate the fact that the IAPH is responsible for several important and distinct outcomes. These include providing an unheard-of degree of support for the training of FNIM individuals interested in Aboriginal health research; bringing greatly increased credibility to Aboriginal health research through its multifaceted efforts; acting as a leader among CIHR institutes in embodying knowledge translation, both with respect to nurturing Aboriginal knowledge and, in the companion arena of bioethics, with development of the CIHR Guidelines for Research Involving Aboriginal People, and; providing support for a growing body of scientifically excellent, high quality, culturally-sensitive health research with Aboriginal people.

Overall impression – to what extent has this Institute been successful in achieving outcomes?

The IAPH has been very successful in achieving measurable and important outcomes in key areas relating to its mandate.

Section 5 - Achieving the Institute mandate

On the whole, and especially given its brief period of existence, the IAPH is achieving its mandate. It has done a superlative job of asserting Aboriginal understandings of health, enhancing knowledge translation and exchange, and advancing capacity and infrastructure in FNIM communities. Most of the Institute's measurable outcomes are found along these domains, and they are certainly fundamentally important areas to focus on.

That said, the Institute recognizes that it must not only continue for gains along these fronts. It must also strive to further increase its support and focus on leading a national, advanced research agenda that fosters innovative, community-based and scientifically excellent research. It was apparent to this ERT in the course of its interviews for this review, that the IAPH also recognizes that it must advance its mission to forge effective partnerships regionally, nationally and internationally. In particular, IAPH leadership and the ERT both feel that national-level partnership needs much greater attention, not least within CIHR.

Overall impression – to what extent has this Institute achieved its mandate?

The ERT deems that the IAPH has achieved its mandate to a considerably admirable extent, though by no means to the fullest extent. As one commentator noted, it has taken many decades to arrive at the current state of Aboriginal health in Canada, and it will take a long process indeed to reverse this trend.

Section 6 - ERT Observations & Recommendations

The Expert Review Team feels privileged to have been asked to critically review the IAPH. In so doing, we have observed that

- Remarkable progress and explicit outcomes in training and infrastructure development have been realized in a relatively brief period of time.
- The IAPH has taken a lead within CIHR in the area of knowledge translation, and in particular development of influential guidelines for the conduct of health research with Aboriginal peoples.
- For such a broad mandate, the IAPH is too underfunded to accomplish much more than it has been doing; it is vital to secure more resources, particularly through greater collaboration and partnership within the CIHR and its member institutes.
- If heightened funding is not to be realized, that the IAPH will be forced to make some difficult decisions vis-à-vis funding training- versus research-focused aims.

Overall impression of the performance of this Institute

The ERT finds the performance of IAPH to be simply superlative, especially given its broad mandate, its very modest level of funding, and its relatively brief period of existence.

Recommendations

- That CIHR fully realize the scope of IAPH's mandate, and respond by funding the IAPH at a level greater than its historically proportionate funding with respect to the Aboriginal population.

- To enhance the Aboriginal health agenda through the fostering of greater collaboration, we recommend that

    - CIHR mandate that each Institute Advisory Board seat an Aboriginal member.
    - CIHR establish an Aboriginal Health Coordinating Committee (or similar), designed to promote and foster an increase in the amount of research performed in Aboriginal settings that is supported by the other institutes.
    - To facilitate the IAPH goal to establish "Community Knowledge Centers" in its next phase, CIHR enable the possibility of funding financially-competent, community organizations.
    - CIHR launch a strategic, pan-institutional health services research initiative in innovative, effective clinical delivery mechanisms to Aboriginal people, requiring the fundamental participation of provincial health service providers.

- That IAPH continue to support the ACADRE-NEAHR centers and network, but to as soon as practical commission an updated comprehensive review of these programs; the results of which can be used for subsequent scale-up decisions.

- That the Institute continues to develop and increase strategic partnerships with Canada's many health charity organizations (e.g., heart, stroke, cancer, etc.).

- That the Institute plan strategically how to manage Aboriginal health researchers' and community expectations in a tight funding environment (e.g., contemplate grant award limits; focus on early career researchers; 2-stage granting processes; partnering with other funding bodies, etc.).

- That CIHR-IAPH look to maximize the inclusion of Aboriginal people in large, national cohort studies (e.g., new child and aging cohorts), and to explore other mechanisms for obtaining a broad description of Aboriginal peoples' health and well-being, whether by improved use of available data, and/or new data collection. Such efforts could represent a transformative vehicle and galvanizing force in advancing the cause of Aboriginal health.

- That IAPH undertake a periodic, fundamental synthesis of its funded research outcomes in order to strive to maximize the lessons learned and knowledge gained, and to look for opportunities to repackage and/or rebroadcast the results of this synthesis for the purpose of enhanced knowledge transfer, particularly with Aboriginal communities.

Appendix 1 - Expert Review Team

Chair - Jeffrey A. Henderson, MD, MPH
President and CEO
Black Hills Center for American Indian Health
South Dakota USA

Expert Reviewer - Professor Linda Tuhiwai Smith
Professor of Education and Maori Development
Pro Vice Chancellor Maori, Dean School of Maori and Pacific Development
University of Waikato, New Zealand

International Review Panel – Professor Fiona Stanley
Director, Telethon Institute for Child Health Research
Chair, Australian Research Alliance for Children and Youth
Professor, School of Paediatrics and Child Health
University of Western Australia
Perth, Australia

Appendix 2 - Key Informants

Session 1 – Review of Institute

1. **Dr. Malcolm King, IAPH Scientific Director**

2. **Dr. Margo Greenwood, Chair – Institute Advisory Board**
   Academic Leader, National Collaborating Centre for Aboriginal Health
   Associate Professor
   Departments of Education and First Nations Studies
   University of Northern British Columbia

3. **Dr. Judy Bartlett**
   Professor/Health Director
   Department of Community Health Sciences
   Faculty of Medicine
   University of Manitoba

4. **Dr. Frederic Wien**
   Member, Make Poverty History Expert Advisory Committee
   Assembly of First Nations
   Advisory Committee on Social Conditions, Statistics Canada
   Nominated Principal Investigator, Atlantic Aboriginal Health Research Program
   Professor, School of Social Work
   Dalhousie University

Session 2 – Consultation with researchers

1. **Dr. Chantelle Richmond**
   Assistant Professor Cross Appointed with First Nations Studies
   Department of Geography
   University of Western Ontario

2. **Dr. Rod McCormick**
   Associate Professor
   Department of Educational and Counseling Psychology, & Special Education
   University of British Columbia

3. **Dr. Laura Arbour**
   Pediatrician, Department of Medical Genetics
   University of British Columbia

Session 3 – Roundtable with stakeholders

1. **Mr. Ian Potter**
   Former Assistant Deputy Minister of First Nations and Inuit Health Branch
   Health Canada

2. **Dr. Suzanne Tough**
   Scientific Director
   Alberta Centre for Child, Family and Community Research

3. **Dr. Andre Corriveau**
   Chief Medical Officer of Health
   Government of Alberta