Kahwaːtsiire*

A RESPONSE TO THE EMERGING CRISIS BETWEEN CIHR AND THE ABORIGINAL HEALTH RESEARCH COMMUNITY

THE ABORIGINAL HEALTH RESEARCH STEERING COMMITTEE
Kahwa:tsire is a Kanien’kehaka word that means both “family” and “all our fires are connected.”

The Aboriginal Health Community Steering Committee is using this word to represent that we have come together from across the country (joined our fires) to address the crisis that exists between the Canadian Institutes of Health Research (CIHR) and the Aboriginal health community.

The word is in a language that only represents one of the many Aboriginal cultures represented by our steering committee. The whole Aboriginal research community includes Métis, Inuit and First Nation researchers, as well as non-Aboriginal persons.

The design on the cover depicts the ‘Kas-wen-tha’ or ‘two row wampum belt’. In Haudenosaunee culture, amicable relations with ‘settler societies’ were maintained through treaties that asserted the respect, dignity, and integrity of each culture and the importance of non-interference unless invited. The purple beads on the belt signify the courses of two vessels — a Haudenosaunee canoe and a European ship — traveling down the river of life together, parallel but never touching. Neither of us will try to steer the other’s vessel. The three rows of white beads between the two rows sets out the principles of the relationship: friendship, respect and mutual benefit.

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For information about this compilation of letters, please contact Fred Wien <frederic.wien@dal.ca>

November 26, 2014.
To: The Aboriginal Health Community and Supporters  
From: Rod McCormick and Fred Wien  
Re: The Emerging Crisis with CIHR and Aboriginal Health Research  
Date: November 24, 2014

We are writing to bring to your attention a serious rift that has developed between the Canadian Institutes of Health Research (CIHR) and the Aboriginal health community. At a time when many public institutions such as universities, SSHRC and others are struggling to develop mechanisms to reflect a new and respectful relationship with First Nation, Métis and Inuit peoples, CIHR seems to be going the other way. It has ended its earlier strong commitment to build capacity in Aboriginal health research; it is eliminating the mechanisms that have previously provided a strong voice for Aboriginal health priorities and perspectives; and it is putting in place new systemic barriers which have the effect of discouraging proposals from the Aboriginal health community in the first instance and subsequently disadvantaging those who have the courage to proceed.

Because of this emerging crisis, we have formed the Aboriginal Health Research Steering Committee (composition in Appendix A following) whose members wrote a series of remarkable letters to the CIHR President and its Governing Council in advance of the latter’s meeting on November 18, 2014. These letters highlight the issues and their significance. To date, there has been no response. We urge you to take the time to read them.

We are also writing to enlist your support, and we provide some suggestions at the end of this memo about what you can do to ensure that CIHR listens to and acts on our concerns. Here, we provide a brief synopsis of what has happened and what is at stake.

When CIHR was first established in the year 2000, its start in building a research base for work in Aboriginal health was promising. The Institute of Aboriginal Peoples Health (IAPH) is one of the 13 institutes that comprise CIHR. IAPH moved with creativity and conviction in its first decade to tackle the need to prepare a cadre of mostly Aboriginal health researchers, to reform guidelines on the ethics of research with Aboriginal peoples, and to engage Aboriginal communities themselves in the research process.

That picture of accomplishment has changed in this decade. The senior leadership at CIHR has seen fit to take the following actions:

- Terminated funding for the celebrated NEAHR program (Network Environments for Aboriginal Health Research). Celebrated for its success by CIHR’s own 2011 International Review Panel, the program has supported dozens of students at any one time, most of them Aboriginal and mostly at the Master’s and PhD levels. Some of its “graduates” have since secured university positions, becoming the future of Aboriginal health research, but in very small numbers. CIHR has done virtually nothing to continue this capacity building work that, as Dr. Judith Bartlett points out in her letter, is necessarily a long-term process when a field is starting from near zero. The effects of failure to continue to support capacity building go beyond the academic sector. Many graduates from Master’s programs have been hired in critically needed policy and research positions within Aboriginal community-based and political organizations. Such employees are critical to First Nation, Métis and Inuit communities being able equitably to participate in academic research.
• Put in place a requirement for a number of its granting programs that applicants not only have to succeed in highly competitive peer review processes but also line up a measure of matching funds from sources other than CIHR. Since this is almost impossible to do in the Aboriginal health field for reasons explained in the last letter following, the effect of this requirement has been to put in place a new systemic obstacle to equitable treatment for the Aboriginal health community.

• Set out on the path to eliminate an Aboriginal-specific peer review process for research proposals. To put it simply, Aboriginal health research is different primarily because it requires the building of trust with Aboriginal communities and the engagement of the latter in the research process from beginning to end. The research process is different enough that an entire chapter in the Tri-Council Policy Statement on Research Ethics is devoted to the topic, and indeed several members of our Steering Committee played key roles in putting Chapter 9 into place. Mainstream researchers on peer review committees who do not have a background in Aboriginal health research are ill equipped to judge proposals, often because the cost and extent of a participatory approach are not realized and several research pillars are addressed in one project. Mainstream peer review committees are often more familiar with system or disease-based review. CIHR is phasing out the Aboriginal-specific peer review committee that has operated successfully in the past in favour of new structures where those with the necessary background may or may not be present. If present, they would be a distinct minority in a process where proposals do not advance unless they receive high scores from multiple reviewers. Again, CIHR will have put in place another systemic obstacle to equitable treatment.

• Carved out almost 50 per cent of its open competition research funding envelope to support stellar emerging and established scholars for longer-term program funding. Again, the Aboriginal health research community is disadvantaged because it is much less well established than other fields such as cancer research or genetics. In addition, the initial screening process places a heavy emphasis on traditional scholarly measures of success, such as the number of publications or research grants. One is challenged to find where those who excel in relationship building with Aboriginal communities and other qualities essential to working in our field would outline this information on the application form. It will be interesting to see how many applications were received from the field of Aboriginal health research, and how many will be successfully funded.

• Decided at its August 2014 retreat that the budget of IAPH and the other Institutes would be cut in half, greatly reducing the scope for IAPH to pursue its own priorities in our distinctive field. The money saved will go into a common pool to which Institutes can apply, but again successful applications are subject to the matching fund rule and our field faces another systemic barrier.

• In August, 2014, Governing Council set out to eliminate the Advisory Boards of each of the Institutes in favour of four clustered Boards. This despite the fact that the Act governing CIHR states clearly that the Governing Council shall “create an Advisory Board for each Health

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1 Sometimes it is stated that in kind contributions will also be considered as part of the package but the emphasis is on the monetary aspect. In any event, Aboriginal political and service organizations have been subject to massive budget cuts in recent years so their capacity to provide even in-kind support is severely constrained.
Research Institute and appoint the members of the Advisory Boards”. While a few Aboriginal health people would be represented on one or more of the clustered boards, we will lose the only advisory mechanism entirely devoted to Aboriginal health and will, once again, be reduced to a situation where Aboriginal voices are a small minority.

- In addition, it appears that the Ottawa-based staff of IAPH will lose their identification with IAPH and become assigned to more general duties. While the IAPH staff, including its Scientific Director, will continue to operate from its base at Simon Fraser University, the reorganization in Ottawa will seriously hamper the ability of IAPH to advance initiatives with other institutes and to communicate with the Aboriginal health research field.

Since there is a pattern here, we are very concerned that the elimination of IAPH itself is the next step, as CIHR moves to develop “a robust framework for the evaluation of the relevance of the Institutes”.

We are not claiming that the Aboriginal health research field is deliberately being targeted by the measures listed above, at least as far as we know. For the most part, the senior CIHR leadership is making decisions with system-wide application and is not taking the time to understand that it has a diverse constituency. System wide policy has quite unequal impacts especially when it comes to the Aboriginal health community.

It is not just our community that is upset. Several Institutes and their Advisory Boards have also expressed their dismay (including the IAPH Board), a sentiment that is likely to increase as the broader research community becomes more aware. Part of the reason for rebellion is that the process that the senior leadership of CIHR has used to make these decisions can only be described as top-down, secretive and disrespectful, as the letter from Dr. Fred Wien describes. Yet, critics are greeted with CIHR public relations speak to the effect that “directions have been set but decisions have not been made” and that “these changes were informed by an extensive consultative process both within Canada and internationally” – patently untrue at least with respect to our field. Critics are then invited to help CIHR implement what has already been decided. Aboriginal people are all too familiar with this tactic and it is infuriating when Ottawa decides and then invites affected community-based staff to attend a training program to implement the changes, all the while calling this “consultation”. Fortunately, the courts have often rejected Ottawa’s misguided process.

Individually and cumulatively, the decisions taken by CIHR and listed above are already having an impact. We hear from senior scholars, including members of our Steering Committee, who refrain from applying to the Pathways Program, for example, on the grounds that they see “not a chance in hell” of being able to receive matching funding. Others do not apply to the new Foundations scheme because they see no reasonable hope of being successful with peer review being stacked against them. Still others are disheartened or angry, including more junior scholars who seek advice on whether they should continue to serve on Advisory Boards or peer review committees.

We wonder what public purpose is served by these measures, which serve to drive the Aboriginal

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2 CIHR web site, Institutes Modernization, November 24, 2014.
3 Message from the CIHR President on Institutes modernization, November 24, 2014
health community away rather than encouraging them to commit with enthusiasm. How do these steps help the CIHR President meet his organization’s system-wide priority as expressed in its Blueprint Strategic Plan to “harness research to improve the health status of vulnerable populations”? And how is this likely to help CIHR fulfill its mandate to “excel, according to internationally accepted standards of scientific excellence, in the creation of new knowledge and its translation into improved health for Canadians, more effective health services and products and a strengthened Canadian health care system”? Especially given the fact that the health and well-being of Canada’s Aboriginal population is arguably Canada’s biggest health challenge?

To conclude, we asked the CIHR President and Governing Council prior to its last meeting to agree without qualification to two simple requests in order to halt further damage and begin the rebuilding process:

“(1) that you make no decisions, or take any steps administratively to implement previous decisions, that would have the effect of further undermining the Aboriginal health presence within CIHR and its programs. An example would be the plan to eliminate the IAPH Advisory Board or to dismantle the Institute of Aboriginal Peoples Health. It would not be adequate nor consistent with the kind of relationship of which we speak to be offered an opportunity to participate in the implementation of decisions that you have already made – decisions that we perceive to be harmful to the Aboriginal health community and made without any meaningful involvement by that community, and

(2) that you agree to participate with us in a process to address and resolve the full range of process and substantive issues that were summarized in Dr. Wien’s letter of 15 November 2014. We envisage that would involve an initial meeting with Dr. Beaudet and other CIHR representatives as appropriate to discuss and agree to an ongoing process of dialogue”.

To date, there has been no response.

What can you do to help?

• Distribute this information package widely among your colleagues, within your department or organization including its members and Board if applicable, and among your networks
• Have a good discussion about the issues raised
• Write a letter, pass a motion or a resolution, expressing your perspective and asking the senior leadership at CIHR to meet with the Aboriginal health community including representatives from the IAPH Advisory Board for substantive discussions with a view to changing course. Ask that your letter be distributed to all members of Governing Council.

Your communication to CIHR should be addressed to:

4 See Appendix B
We also encourage you to write us or copy us on your communications using the e-mail addresses provided below.

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November 17, 2014

An Open Letter to Dr. Alain Beaudet, President, the Hon. Michael Wilson, Vice-Chair of the Governing Council, and Other Members of Governing Council
Canadian Institutes of Health Research

I write this letter in my role as a Professor in the Department of Medical Genetics at the University of British Columbia, and as an aboriginal health researcher. As a Medical Geneticist and Pediatrician, my work exploring the interconnection between the biological, environmental and social determinants of aboriginal health predated the onset of the CIHR. This focus of research was a result of my experiences as a pediatric consultant in northern Canada where it was evident that the genetic component of health in aboriginal peoples (with the exception of diabetes) was often ignored. At the time of the initiation of the CIHR there was great international indigenous concern over the health disparities suffered by indigenous peoples, but addressing those issues with research was overshadowed by the common disregard of researchers for the needs, outcomes and capacity building within aboriginal communities and populations. Unfortunately notorious, unconsented secondary uses of stored biological samples from aboriginal health research studies provided the justification for several communities in North America, including Canadian communities, to declare a moratorium on genetic research.

The forward thinking of the onset of the CIHR saw a different way of doing things. The CIHR led the way internationally in challenging the paradigm that it was acceptable a certain part of the population should have worse health outcomes. They also led the way in breaking down the paradigm of the academic ivory tower being the sole proprietor of research data and biological samples. In other words respect for aboriginal persons and populations were reflected in priority goals for improved aboriginal health outcomes, involvement in all research steps, building aboriginal research capacity, and the consideration that research data and sample collection are an extension of the collaborative process. Aboriginal peoples of Canada wanted a collaborative approach, and the CIHR listened to them. The respectful methods developed with aboriginal peoples and deemed accepted within the CIHR were considered ‘cutting edge’ internationally, and respect followed downstream to our universities, health care organizations and others. The CIHR leaders of that time, felt that an emphasis on addressing disparity from within, with integrated knowledge translation, would result sometime down the road, in improved outcomes.

I have had the opportunity to speak nationally and internationally about the CIHR’s visionary and ethical approaches to research with aboriginal peoples. These presentations, by invitation, included the London School of Economics, the Universities of Southern California and Arizona, Cold Spring Harbor Laboratory in New York, the US Government’s Secretary’s Advisory Committee on Genetics Health and Society amongst others. The forward thinking approaches to biological research within aboriginal communities, while addressing the wrongs of the past were featured in Nature and Science magazines (see below). The scientific world has taken notice, including the large international Washington DC audience of the American Society of Human Genetics, who heard Dr. Rod McInnes feature in his Presidential Address, the advances in genetic research in aboriginal populations made possible by the CIHR’s policies. As you know, Dr. McInnes was the inaugural CIHR Scientific Director of the Institute of Genetics. For his high profile presidential address he could have spoken on any topic, but he chose to
An Open Letter

speak on how the CIHR was changing the way research could be done with indigenous populations. A quote from the 2011 published proceedings: "You may be surprised to learn that one of its 13 Institutes is the Institute of Aboriginal People’s Health (IAPH). The establishment of this institute, in 2000, is making a huge impact on support for research, and the conduct of it, in aboriginal communities in Canada (McInnes 2011)". He was preparing the world for a new way of carrying out genetic research within indigenous populations; one that was protective, enabling for all involved and led by the CIHR. No doubt his profiling of this work is having an impact internationally.

Realistically, barriers are only beginning to be broken down to allow multifaceted, scientifically rigorous research to be carried out in partnership with indigenous communities. Unfortunately the gradual erosion of the respect for the special circumstances of aboriginal research within the CIHR in the last 7 or 8 years is starting to become evident beyond the CIHR, and will become more evident as aboriginal health research is absorbed quietly and politely into the CIHR agenda. The added funding needed for appropriate consultations and ongoing participatory processes are in danger of being considered a luxury, rather than a necessary standard. The pending elimination of the IAPH and the aboriginal peer review committee which follows the elimination of the NEAHRs will risk that aboriginal health in Canada not only significantly loses ground in any progress made, but will demonstrate to those watching that a collaborative, partnership approach is not worth trying. CIHR stands to lose its international reputation as one that recognizes that scientific research can be done well in a collaborative manner, with communities (not on them).

Personally, if the CIHR aboriginal health focus continues to spiral downward, as a researcher, I will still be able to work and be competitive. I could re-focus on other research as will many other aboriginal health researchers. The loss will be in the differences that could be made with a focus on aboriginal health. As academics working in aboriginal health we have a responsibility to speak out against changes that will allow the shameful health disparity gap to persist in Canada, one that needs, in part, to be addressed by research. The changes underway at the CIHR need to be carefully thought through in that context.

Sincerely,

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References:

*Select International Invited Presentation featuring the work of CIHR and its application:*


Nutrient/Genetic Determinants of Birth Defects in Northern Canada: Challenges to carrying out research with an aim to improve outcome", 8th National Australian Rural and Remote Health Conference. Alice Springs, Australia, March 2005

Canadian experiences carrying out genetic research with aboriginal communities" Fort Yates, North Dakota, Northern Plains Epidemiology Center, June 2005

DNA on Loan: Approaches to Carrying out Genetic Research with Aboriginal Families and Communities" Institute for Public Health Genetics Seminar Series, University of Washington, Seattle, WA, January 2006

Genetic Research with Canadian Aboriginal populations“ Alaska Native Health Conference, Anchorage Alaska, March 2006 - Keynote speaker

“Genomics and Justice: Genetics Research with Canadian Aboriginal People” University of California, Santa Cruz, US, May 2007 (published online)

“DNA on loan and indigenous governance of genetic research” Indigenous Governance workshop, Arizona State University, Tempe Arizona, November 2008


A view from Canada, Genetic research with Northern Aboriginal populations: Danish Greenlandic Society of Circumpolar health Meeting, Copenhagen Denmark, April 2010-Keynote speaker

Genetic conditions, birth defects, and a new approach to research with aboriginal people of Canada, David Smith Workshop on dysmorphology and morphogenesis: Keynote speaker: Hood Canal, Washington, August 2010

Canadian Policies that address the Involvement of Groups in Genomic Research and Data Sharing. for the US Government: The Secretary’s Advisory Council on Genetics Health and Society (ACGHS) Genomic Data Sharing Task Force October 6, 2010, NIH Bethesda, Maryland.


Other references:


Couzin-Frankel J. Researchers to Return Blood Samples to the Yanomamö Science, June 2010: 328(5983)1218

An Open Letter to Dr. Alain Beaudet, President, the Hon. Michael Wilson, Vice-Chair and all Members of the Canadian Institutes of Health Research Governing Council

By way of introduction, I am a Metis physician researcher. I was on the IAPH inaugural advisory board and felt extremely privileged to be able to play such a role. The IPAH board’s core objectives included: 1) creating, developing and supporting Aboriginal health research partnerships at the local, regional, national and international levels; 2) building research capacities in Aboriginal health research; 3) influencing CIHR corporate functions of ethics, peer review, and knowledge transfer; 4) initiation of strategic initiatives. The institute work was intended to address and narrow the gap in health status between Aboriginal and other Canadians through development of health research capacity at both the Aboriginal communities and university institutions levels. In this open letter, I will cover several areas of critical importance to the need for continuation of First Nations, Met and Inuit health research capacity development posed in a series of questions.

Why has CIHR policy direction changed before the specialized field of Aboriginal health research has had opportunity to fully articulate its core principles, methodologies and methods of research when other fields of study have had many decades to formulate and discuss such key issues?

Much more time is needed to fully articulate and implement Aboriginal health research. A specific example of how long it takes Canada to move from idea to policy resides in the near 40 years required to politically engage health policy to move from disease care to prevention/promotion: Rowell-Sirois Commission (1939); World Health Organization (1947); Lalonde (1974); Blum (1974); Dever (1979); and finally the Ottawa Charter (1986). It has taken health promotion another 30 years to become embedded within the general population psyche.

Can we learn from our previous research and discussion on important public health issues?

In Ilona Kickbusch’s opening chapter of the book ‘Health Promotion in Canada’* she began with a story. Kickbusch states, “If people learn from stories, successful health promotion must be able to tell stories that relate to their experience; stories that give a possibility for ownership and identification, that give courage for change; stories about where people live, love, work, and play -in short, about everyday life.” Kickbusch was speaking of the intent to change the course of people’s lives to mitigate or eliminate chronic health conditions that are so costly in human and financial terms. It is my contention that Kickbusch’s statement is equally valid for health research and knowledge translation.
In First Nations, Metis and Inuit communities, KT is about ownership and the propensity to use this ownership to advocate for and/or make change in peoples’ lives. It is well understood that the best and easiest learning always begins with a question. But a question must begin with “stories that give a possibility for ownership and identification, that give courage for change.” If CIHR is truly committed to improving Aboriginal health, it must continue with the process of creating an environment where stories, ownership and courage can flourish.

If CIHR Governing Council, made up of our greatest Canadian health research thinkers, cannot advance equity for Aboriginal Peoples, then who will?

Premature mortality for Metis in Manitoba is 21% higher than all other Manitobans (Metis Atlas, 2010). In 2006, Statistics Canada data showed that 69.5% of Aboriginal Winnipeggers versus 38.7% of general Winnipeggers (age 15 and over) had an income of less than $20,000 annually. The median income for the Aboriginal population 15 years and over was $19,672. In comparison, Winnipeg’s general population reported a median income of $27,061. The same 2006 data show that similar proportions of Aboriginal (77.4%) and general Winnipeggers (76.5%) received their income from employment. Aboriginal Winnipeggers’ employment rates have increased and unemployment have decreased between 1996 and 2006, but it is very clear that the serious wage gap remains.

The 2006 census year is the last glimpse we will have of First Nations, Metis and Inuit health status in Canada. One thing is certain in any country; it measures what is important to the governing party. Unfortunately, the CIHR is moving in the same direction as the current federal government to eliminate any ability to measure the health status of First Nations, Metis and Inuit populations. I suppose the old adage of ‘if it’s not written down, then it did not happen’ will serve as a good excuse when the world begins to examine and criticize the underlying tenets of Canadian society. “We didn’t know” just won’t fly!

Why are Aboriginal people expected to be ready to overcome centuries of negative political, social and economic forces without adequate research preparation time?

I consider myself, by reason of poverty circumstances and lack of early life opportunity, a late bloomer in medicine (10 older than peers) and as a researcher. I am in the later part of my research career but there are many young First Nations, Metis and Inuit students who might love to have a research career. They should not have to miss out on such opportunity. I just cannot understand what GC must be thinking; how they can decide that enough support has been given and now Aboriginal researchers are on their own.

In addition, not only will the new CIHR policies eliminate the health research capacity development for First Nations, Metis and Inuit populations, it will be a significant loss of research capacity development within the universities. Such academics will not have opportunity to undertake First Nations, Metis or Inuit health research since there will be few communities that are prepared to take on the role of community collaborators and/or research partners. This preparation is created by First Nations, Metis and Inuit academic health research graduates who take on community roles in research. Such graduates play a critical role in supporting communities to develop sound relationships with academically positioned researchers.
I have to say that at no point in my life journey have I felt quite so disappointed in Canada. Aboriginal people are expected to achieve in a few short years what has taken many generations for the general Canadian population to accomplish. Our prospects for continuing the journey to culturally appropriate research equity is wiped away. I cannot fathom, given the atrocious gap in health status and income between First Nations, Metis and Inuit Peoples and other Canadians, why small research investments cannot be identified. It is clearly unreasonable that CIHR would expect that First Nations, Metis and Inuit, who have been forced to exist on the margins of society for centuries, to do a catch up in the field of health research in just 15 years of sustained support and mentorship.

With the loss of the ability for Statistics Canada to undertake population health and social research that includes First Nations, Metis and Inuit populations CIHR funded health research is even more essential.

**CIHR is well positioned in a research leadership niche in Indigenous health that can have many positive impacts globally?**

There are an estimated 370 million Indigenous people globally in 70 countries. CIHR, through IAPH, should continue with its leadership in the area of Indigenous health research internationally. With IAPH leadership in early development, and continued collaborations through IAPH sponsored research, we have seen the development, implementation and sustaining of the International Network of Indigenous Health Knowledge and Development (INIHKD) (2001-current) that had its’ 6th biennial conference in Winnipeg Oct 5-10, 2014. In attendance were 400 researchers, community members, policy and program developers and deliverers from Canada, Australia, New Zealand/Aotearoa, and the United States. There were 185 oral presentations, workshops and poster (63, 16 and 31, respectively, from Canada). The network continues to grow with new countries becoming involved this year - Colombia, Chile, Taiwan, and Africa. Continuing increases in the countries wanting to participate in the INIHKD shows that the environment is primed for continued Canadian leadership in Indigenous health research worldwide.

In the end, it would be in the best interest for the CIHR to retain the positive international reputation in Indigenous health leadership. Creating one more barrier to First Nations, Metis and Inuit Peoples to climb out of the deplorable situation in Canada will be regretful.

Cordially,

Judith G. Bartlett MD, MSc., CCFP
Associate Professor
College of Medicine
University of Manitoba

An Open Letter to Dr. Alain Beaudet, President, the Hon. Michael Wilson, Vice-Chair of the Governing Council, and Other Members of Governing Council Canadian Institutes of Health Research

I am writing this letter as an Indigenous community-based health researcher who works proudly for one of the only Indigenous post-secondary institutions in Canada. We are here to serve Indigenous communities – to undertake research with, by and for them – to improve the health of their communities based on their needs. I have had the privilege of working with some of the most incredible Indigenous communities, Elders, leaders, youth, advocates, allies and researchers in the country.

CIHR has had an incredible impact on health research in Canada and, in particular, Indigenous health research particularly through the creation of the Institute of Aboriginal People’s Health (IAPH). Having our own institute allowed the necessary focus on the complex health disparities facing Indigenous people across Canada – disparities that could only be explained by examining the interaction of social determinants of health including the ongoing effects of colonization.

Incredible strides were made and as a junior researcher at the time, I was humbled to be mentored by some of the most incredible Indigenous pioneers and allies including Dr. Eber Hampton, Dr. Jeff Reading, Dr. Rod McCormick, Dr. Frederic Wien, to name a few. However, the recent changes including the funding restructuring that has seen the sunsetting of the ACADRE/NEAHR program this past March and the new strategic grants that require funding from other sources are of great concern to me. Most of us working with Indigenous communities do not have access to matching funds particularly as the communities we work with have seen sweeping cuts to their budgets. The sunsetting of the ACADRE/NEAHR program puts any capacity building with our communities in jeopardy and ensures that our graduate students, many of whom are already a different demographic from non-Indigenous students (ie. May be older, may have children, may have fewer social supports) may not be able to continue in their studies. Considering we already have difficulty recruiting Indigenous students into graduate health fields, this is a serious concern.

There is another structural concern that I would like to raise. I sat on CIHR’s Standing Committee on Ethics for two terms (6 years). When I began, Dr. Harvey Chochinov was the Chairperson and there was a designated position for an Indigenous expert. The SCE was very actively engaged and we met in person twice per year and had several decision items. We were very proud to publish and disseminate CIHR’s Guidelines for Health Research Involving Aboriginal People and we had excellent discussions on how we could provide training to REBs across Canada regarding research ethics and protocol with Aboriginal people. However, as I began my second term the role of the SCE began to change and we could tell that our role would change significantly. Over the next few years our meetings were less about decisions and more about information items. Our face to face meetings were reduced and in the last year that I served our committee membership was dissolved and a new, smaller committee formed. One of our committee members was nominated to the new committee. The rest of us were
thanked for our service and sent a lovely certificate. My two terms were up and I was on my way out but I was very upset that the Indigenous expert position was eliminated on the new committee. I brought this up several times and e-mailed our Chair, Dr. Nicole Letourneau who assured me my concern would be passed along to GC. I want to note that I was not the only one with this concern. The entire committee felt it important to ensure the new committee have an Indigenous expert (even though I dislike the title) – it is important to continue to have Indigenous voice in something so important as research ethics. We cannot assume that our voice will be represented. We cannot assume that all researchers understand and respect Indigenous community-based research methodology, ethics and protocols. We are not yet at that place where we can say we have reached equity and until we can say that we still need these positions, we still need IAPH, we need directed Aboriginal grants. This is our reality for now.

With respect,

Carrie Bourassa, PhD, FRSC
Professor
Indigenous Health Studies
Special Advisor to the President, Research
An Open Letter

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An Open Letter to Dr. Alain Beaudet, President, the Hon. Michael Wilson, Vice-Chair of
the Governing Council, and to Other Members of the Governing Council
Canadian Institutes of Health Research

This letter adds my voice to the chorus of researchers in Aboriginal health urging the Governing
Council of CIHR to re-think the direction and the consequences of a series of decisions recently
taken or pending which will critically alter the environment of Aboriginal health research in
Canada and undermine the advances achieved over the past 15 years.

Letters going to Governing Council from colleagues in the research community set out the
specifics of policies and processes that are already having a corrosive effect. My comments draw
on lengthy experience and take a long view of the repeating pattern that has deflected or ignored
the contribution of Aboriginal peoples to improve the health status of their diverse population.

My professional experience goes back to 1956 as a solitary Mohawk social worker in child
welfare, arguing against the imposition of urban, Anglo-American norms to “help” Indian
children. I didn’t have the data or the breadth of vision to know that the “sixties scoop” was
already underway rescuing children at risk by removing them from families devastated by
residential schooling.

Fast forward to 1973 when I had the enormous privilege of joining the Department of Native
Studies emerging at Trent University. For the first time, Aboriginal peoples had a tiny niche in
academe, where their students could study their languages and histories and examine their
contemporary situation in the context of a largely colonialis-t environment. The remarkable
discovery was that, given the chance, scores and even hundreds of students of Settler origins
chose to pursue Native Studies to enlarge their own intellectual and ethical purview.

Forty years later Indigenous Studies has found a place in virtually every university and college in
Canada, where institutions are recognizing that the dearth of Aboriginal students and graduates
that prevailed was due not to the limited intelligence of Aboriginal people (as was assumed in
earlier days) but to the structural and attitudinal barriers that served to interfere with post-
secondary access and retention.

My involvement in community development and community-based research at Trent led to my
appointment as Co-Director of Research with the Royal Commission on Aboriginal Peoples
(1992-96). The extensive research program of RCAP was committed from the outset to engaging the participation and wisdom of Aboriginal people themselves in concert with academic scholarship. Ethical guidelines for research were adopted to protect against uncritical privileging of outsider perspectives infused in existing literature and expert research practice. I think it is fair to say that RCAP, along with concurrent social, political and constitutional change, stimulated an upsurge of interest and trust in research within the Aboriginal population and determination to “research ourselves to life.”

Hope that research could be a tool to reclaim human dignity and well-being as Aboriginal peoples was fuelled by the response of the health research establishment to create the Institute of Aboriginal Peoples’ Health as one of the CIHR institutes. The approach of IAPH, engaging Aboriginal communities, fostering capacity-building at the ground level and providing entry points for the formation of young researchers, succeeded in reducing distrust and creating networks of informed and committed partners and volunteers connected to the NEAHRs across the country. IAPH, with the support of CIHR Ethics Office, spear-headed dialogue, development and community endorsement of CIHR Guidelines for Health Research Involving Aboriginal People (2007) which became a platform for drafting and gaining cautious acceptance by Aboriginal participants of the dedicated chapter on Aboriginal research integrated in the second edition of the TCPS (2010).

At this point you may be asking: What is the point of this stroll through history? As always, the point of considering history is to learn from it. Some of the lessons I would underline are:

1. Interventions to alter disparities in health status of Aboriginal peoples, as with education and child welfare, are destined to be ineffective and possibly harmful without the engagement of the people themselves.
2. Respectful relationships with professionals and institutions release energy and creativity in the Aboriginal community, provided there is flexibility to adapt processes to cultural values and behavioral norms. Niche programs are like a fire around which we gather to warm ourselves and bring our minds together as one before going back to the challenges of keeping the world in balance.
3. It takes time to effect social change. It has taken 40 years for Indigenous Studies to gain a (sometimes contested) foothold in higher education. We have only begun to make inroads in elementary and secondary education that still largely ignores Aboriginal presence.
4. The “start-and-stop” pattern of programming arouses hope and then dashes it. We documented this pattern in RCAP research in numerous domains. Synergies and
voluntary effort contribute to successful outcomes. When the program is terminated
infrastructure is dismantled. Participants’ learning is interrupted. Employees disperse to
jobs unrelated to their developing capacity. Institutional memory is lost. The pattern is
extremely wasteful of material resources and social capital, e.g. the dismissal of RCAP’s
Report and research legacy; the termination of the Aboriginal Healing Foundation and its
animation of community healing; the radical downscaling of NEAHRs.

I hope that the stories recounted in this letter and others going forward move the members of
CIHR’s Governing Council to seriously reconsider the course on which CIHR has embarked: to
modify administrative and advisory structures and review processes in ways that will inevitably
mute the distinctive contribution of IAPH to the overarching goals of CIHR.

Most sincerely,

Marlene Brant Castellano

Marlene Brant Castellano, O.C., O. Ont., M.S.W., LLD
Professor Emerita of Trent University

November 16, 2014
An Open Letter to:

Dr. Alain Beaudet, President, Canadian Institutes of Health Research and to the Honorable Michael Wilson, Vice-Chair of the Canadian Institutes of Health Research Governing Council and Other Members of Governing Council

November 25, 2014

I am writing this letter to express my concerns about changes occurring within the Canadian Institutes for Health Research (CIHR). I am particularly concerned about the impact of those changes on the Institute for Aboriginal People’s Health.

I write this letter from my position as an Indigenous Cree woman scholar and Full Professor in the First Nations Studies and Education Programs at the University of Northern British Columbia. I also bring my experience as an Advisory Board Member and Past Chair of the Institute for Aboriginal People’s Health as well as my current positions as Academic Leader for the National Collaborating Centre for Aboriginal Health (which I have held for 10 years) and Vice-President Aboriginal Health in the Northern Health Authority in British Columbia. These positions offer me more than two decades of personal and professional experience from which I speak about the vital importance of having accessible, quality, and impactful research specific to First Nations, Inuit and Metis peoples in Canada.

I will not reiterate the many important points made by Indigenous and non-Indigenous scholars and colleagues, from across the country, who have highlighted the losses and perils of not having a specific CIHR Health Institute dedicated to knowledge and research for and about Aboriginal peoples. Indeed, there is wide agreement that without this kind of culturally specific knowledge and research, little chance exists to address what is understood nationally and internationally as one of the globe’s most pressing socio-cultural, economic, and health divisions: the divided state of well-being between Indigenous and non-Indigenous peoples in Canada. When one considers the actions of transforming CIHR alongside the ongoing state of Aboriginal people’s health in Canada, one cannot help but call out for new, evidence-based, and innovative ways to address disparities and inequities that exist. These must begin by providing high quality, culturally respectful, and relevant evidence to practitioners, decision makers and Aboriginal people ourselves as one step toward addressing our health needs. Doing this requires specific and unique, as opposed to integrated, knowledge production, translation, and dissemination.
For the past decade I have had the privilege of focusing my scholarly energies in the area of knowledge translation and dissemination. These activities have afforded me an acute and heightened appreciation for research and the critical role it plays in stimulating and supporting interventions focused on realizing optimal health and well-being of Aboriginal peoples in Canada. Research production and knowledge translation must remain intimately and productively intertwined – knowledge must flow to Aboriginal peoples for health inequities to change. The transformation and change required to address whole population disparities requires not only the individual research efforts but also the national infrastructure to support such endeavors.

I am of the opinion that the structural changes occurring within the Canadian Institutes of Health Research seriously jeopardizes Canadians’ (writ large) ability to address the single most significant health disparity in the country – Aboriginal health. Only a specific, multi-level, focused, and longitudinal effort will address this disparity.

I urge the Governing Council to reconsider their intent to ingrate and constrict Aboriginal health research. I urge you to protect the unique and specific Institute of Aboriginal People's Health so that we may all reap the benefits of a mature and integral centre in years to come. I urge you, in short, to keep in mind the interests of Aboriginal peoples and our communities: there are generations of Canada’s most marginalized peoples.

Please accept my thanks in advance for taking seriously not only my voice, but the voices of Inuit, Metis and First Nations peoples from coast to coast to coast in Canada.

Sincerely,

Margo Greenwood, PhD
An Open Letter to Dr. Alain Beaudet, President, the Hon. Michael Wilson, Vice-Chair of the Governing Council, and Other Members of Governing Council
Canadian Institutes of Health Research

I know this is likely one of dozens of letters you will receive about CIHR’s recent decisions that will influence Aboriginal health research in Canada. So, I appreciate you taking the time to read it. I have decided not to list all of the achievements and missteps CIHR has made in the past 14 years, as I’m sure you know them better than I do. Rather, I would like to share how they have shaped my experiences as an Aboriginal health researcher.

When I began my Master’s thesis research, which included older women who are racialized as White, Black or ‘Native’, most of my colleagues and professors couldn’t imagine why I would explore the cultural influences of women’s experience of menopause. My PhD research (with Mik’maq women only this time and for which I received SSHRC funding) began with the same perplexed questions, “Why would Native women have a different experience of menopause than anyone else”? “How could ‘their’ health needs be any different?” At that time, concepts like social determinants of health, cultural safety, and the influence of racism on health were not part of our Canadian health research lexicon. Yet, with the creation of the CIHR-IAPH in 2000, all that changed.

In 2002, I was invited by Dr. Fred Wien (my PhD supervisor at the time) to join him and others in applying to the ACADRE program (the precursor to the NEAHR Program) so that we could provide support for students, researchers and communities to engage in the kind of research we had been doing with, for and by Aboriginal collectivities and communities. During the next 10 years, I witnessed a transformation in not only Aboriginal communities’ willingness to partner in research but also in the role they were able to take in leading the direction as well as engaging in the process of research that was relevant and useful to them. I can honestly say that being part of the ACADRE/NEAHR program set me on a career path of Aboriginal health research, with a special interest in HIV/AIDS. I was also fortunate to work with dozens of students, and through ACADRE/NEAHR support many others, who were pursuing training that would prepare them to work respectfully and productively with Aboriginal peoples. Each year, IAPH and the NEAHR Centres hosted a gathering for those students to network and share their work. Through these and other initiatives, we began to form a network of researchers across the country, united in our shared goal of contributing to the health of Aboriginal communities. I have been privileged to be part of that network (Aboriginal Health Research Network) as well as the Chair (2008–2013) and grant holder (2010–2013) of its Secretariat, which supports national as well as international Indigenous research collaborations.

The ascending research capacity and engagement trajectory began to change in 2013, when it became clear that CIHR was adopting a ‘level playing field’ approach. One, similar to the ideology of ‘colour-blindness’, that presumes Aboriginal researchers experience the same demands and supports as other researchers and - that the playing field is actually level. In reality, this approach perpetuates inequities because it does not recognize that Aboriginal research, in fact, takes more time, energy, and resources. Similarly, it does not consider the distinctly
An Open Letter

powerful affect of policy on not just how but if Aboriginal health research is undertaken.

We also came to understand that our work would require substantial investment by industry partners that we simply couldn’t attract or that would not be acceptable to Aboriginal communities. We simply can’t justify why we must partner with the very industries that are harming them or their fellow nations. It is not surprising that communities are, once again, becoming distrustful of our system of research funding and consequently, of research itself. Where they once approached us enthusiastically to engage in research, now they remain silent or respectfully decline. Loss of regional-level support and mentorship has also reduced the number of students who approach me about a career in Aboriginal health research. Changes in CIHR’s funding and advisory process as well as the sun setting of critical research capacity development supports will undoubtedly generate fewer new researchers and damage relationships with community, all contributing to what I fear will be a perilous downward trend in Aboriginal health research.

Our work in this field is challenging and takes a toll on personal lives and professional ‘achievements’ but until recently, the outcome was worth the effort. That has changed. In fact, the future seems bleak and I’m not sure how much longer we can continue within the current structure. We gained so much ground in the past 10 years that it’s rather heartbreaking to see it lost so quickly.

I know you are just one person and that speaking against those with power can be difficult and intimidating. But your voice is important and I’m asking you, humbly, to listen to our words with an open mind and to join our collective appeal for equity.

Sincerely,

Charlotte Loppie (Reading) PhD

Professor School of Public Health and Social Policy
Director Centre for Aboriginal Health Research
Editor International Journal of Indigenous Health
An Open Letter

November 15th 2014

An Open Letter to Dr. Alain Beaudet, President, the Hon. Michael Wilson, Vice-Chair of the Governing Council, and Other Members of Governing Council
Canadian Institutes of Health Research

I am writing this letter to you with knowledge gained from working with Aboriginal peoples for 44 years: first as a practicing family physician since 1970 and then as a researcher since the early 1980’s. During these years I have come to understand the very severe obstacles that Aboriginal people and Aboriginal organisations have had to overcome in Canada.

My experiences include serving as an IAPH Institute Advisory Board member for six years, which included both Dr Jeff Reading and Dr Malcolm King as Scientific Directors, contributing to developing ethical guidelines for researchers in partnerships with Aboriginal communities long before those of CIHR and the Tri-Council Policy Statement, as co-investigator of one of the ACADRE/NEAHRs, reviewer for early peer review panels and Chapter 9 of TCPS, 20 years of leadership of the Kahnawake Schools Diabetes Prevention Project that was awarded the CIHR Partnership Award in 2010 for combining scientific rigour with cultural relevance, and committee member for Masters and PhD students including Aboriginal postgraduates funded through the ACADRE/NEAHRs.

I was a one of the researchers who fought hard that CIHR should include an institute dedicated to Aboriginal health. I well remember a McGill colleague who told me that ‘it did not make sense to have an institute dedicated to Aboriginal health because there was not enough Aboriginal research and any Aboriginal research that existed was of very poor quality.’ I responded that those were the very reasons that there should be an Aboriginal Institute as there was enormous need to train more researchers - especially Aboriginal researchers - and increase the quality of the research so that future interventions and health programming be made using high level research results. There was also a glaring need for research to respect Aboriginal peoples and communities, for research ‘with’ communities and not more research ‘on’ or ‘about’ communities, for research to evaluate Aboriginal strengths and resilience and for ethical guidelines to ensure researchers had to adhere to developing respectful research partnerships. It was so very exciting when Canada showcased their support of Aboriginal research to the world through the development of IAPH.

The presence of IAPH, dedicated funds for capacity building through the ACADRE/NEAHRs, dedicated funds for Aboriginal research, the Aboriginal peer review committee, and Aboriginal reviewers including community members, have all made enormous contributions to improving research standards and relevance, building capacity, and re-gaining Aboriginal peoples trust.
What is less well recognised is the wider applicability of many of CIHR Aboriginal developments. Many researchers outside of Aboriginal health have been inspired by examples and experiences of Aboriginal health researchers developing partnerships ‘with those affected by the issue under study’ and ‘those needing to act on the results’. They also recognise that respectful research partnerships support faster knowledge translation, increased capacity of researchers and community members and unexpected and positive ‘spin-off’ benefits. Many researchers have also been inspired by and use the Aboriginal chapter 9 of the Tri- Council Policy Statement in their research when partnering with vulnerable (non Aboriginal) populations.

I fully endorse all the points that Dr Fred Wien has included in his letter. He has succinctly summarised the current issues and outlined the negative consequences that current decision making at CIHR will have on the future of Aboriginal research. Lack of financial support of young Aboriginal researchers and for overall Aboriginal research will dramatically erase the benefits of the past capacity building of the ACADRE/NEAHRs. I have witnessed the unique strengths of those young Aboriginal researchers who combine excellent training in research methodology with their own Aboriginal identity and unique community knowledge. They are extremely well placed to undertake key research to reduce Aboriginal health inequity – one of the glaring needs of this country - as highlighted by CIHR’s International Review Panel and the report of the United Nations Special Rapporteur on the Rights of Indigenous Peoples.

Why has CIHR made all these changes at the same time as SSHRC, who in great contrast, has developed an Aboriginal Advisory Circle to provide guidance on their programs and policies for Aboriginal peoples?

It deeply saddens me today that CIHR has now become one of the institutions in Canada which has become very disrespectful of Aboriginal peoples and the crying need to reduce health inequities.

To those of you on the CIHR Governing Council I invite you to carefully review all these letters with the multitude of experiences and recommendations. In addition I respectfully ask you to meet with us to discuss these issues in depth and to make the changes necessary at CIHR to better support Aboriginal research. Without changes Aboriginal research in Canada will return to time that existed before the development of the CIHR Institute of Aboriginal Health.

Yours sincerely,

Ann C. Macaulay CM MD FCFP FRCPC (Hon)
Professor of Family Medicine
Scientific Director, Kahnawake Schools Diabetes Prevention Project
Inaugural Director, Indigenous Health Curriculum, McGill University
To All Members of the Governing Council of the Canadian Institutes of Health Research
Chair, Dr. Alain Beaudet
Vice Chair, the Honourable Michael Wilson
With special attention to Dr. Nadine Caron
Please distribute to all members of the CIHR Governing Council.

Friday, November 14, 2014

Re: Policy changes to CIHR Institute of Aboriginal Peoples’ Health.

Dear Chair and Governing Council of the Canadian Institutes of Health Research;

She:kon Skennen’ko:wa ken

I am writing to you with a sense of urgency to add my voice to that of other senior Aboriginal health researchers to ask you to reconsider taking any further actions that may result in the dismantling of the pillars of Aboriginal health research in Canada. To provide context for my request I will organize my thoughts within an Indigenous problem solving framework I have been taught to use by briefly looking at where have we come from, where are we now, and where are we going to.

Where have we come from?

In the past when Aboriginal and non-Aboriginal peoples in this country have engaged in relationships involving research it has been a relationship of research being done on us. This form of research continued well into the 1950’s as recently revealed by Canadian food historian Ian Mosby. Mosby found that 1,300 Aboriginal people — most of them children — were used as test subjects in the 1940s and ‘50s by government funded researchers looking at the effectiveness of vitamin supplements. Subjects were kept on starvation-level diets, and given or denied vitamins, minerals and certain foods. Some dental services were also withheld because researchers thought healthier teeth and gums might skew results. This terrible legacy of research slowly evolved over the next few decades to the point that research was being done for us by non-Aboriginal researchers who had entered into partnerships with Aboriginal communities and organizations.

With the coming of CIHR this somewhat lopsided relationship rapidly evolved further to research being done with us in a meaningful way. It was with great excitement that I was invited to be part of this progressive evolution 14 years ago as a founding board member on the brand new Institute of Aboriginal Peoples Health. Centuries of research exploitation and marginalization of Aboriginal peoples now had a chance to be transformed as the national health research organization of Canada recognized that Aboriginal peoples were best suited to determine our own re-
search priorities. With feelings of pride and respect for CIHR, I served 2 terms as a board member for the IAPH; for numerous years on our own Indigenous peer review boards/panels; and for over 10 years as the leader of the BC ACADRE and NEAHR. I didn’t hesitate when asked by CIHR to serve on an SD hiring panel, for CIHR press meetings, for delegations forming international partnerships, for consultation for the International reviews etc. as I sincerely believed that Aboriginal people were a respected partner within CIHR and that we were moving to a point with our capacity building NEAHRs that Aboriginal health research would one day be done by us as opposed to on us, for us, or with us. Most importantly we were slowly overcoming the centuries of mistrust that Aboriginal peoples of Canada had towards research.

Where are we now?

It seemed like just a few years ago that I boarded 3 increasingly larger planes to Ottawa (including a red eye flight) to give testimony at the 2011 International Review of CIHR, only to immediately turn around and take 3 planes back to a remote island off the west coast where I was leading an intensive trauma recovery program for Residential School Survivors. In my submission to the Expert Review Team I stressed that the secret to CIHR’s success in creating a meaningful research environment for Aboriginal peoples was the existence of our own Institute of Aboriginal Peoples Health with our own Indigenous Advisory board, with control over our own strategic dollars, with the existence of our own Indigenous review board, and with the existence of our capacity building tools-the NEAHRs and AHRNETS. Not surprisingly the Expert Review team report recognized the success of these elements and found the “performance of IAPH to be simply superlative, especially given its broad mandate, it’s very modest level of funding, and its relatively brief period of existence”. The IAPH was at that time the envy of the slowly evolving Indigenous research initiatives in countries such as Australia, New Zealand and the United States.

Flash forward to last month when I attended an International Indigenous health meeting in Winnipeg with senior Aboriginal health researchers and government administrators from these same 4 countries. I sat there embarrassed and ashamed at how far Canada’s Aboriginal health research culture has diminished over just a few short years. The Canadians present didn’t talk of what has happened to us perhaps out of a similar sense of shame or perhaps from an unwillingness to publically reveal that we are no longer the world leader in Aboriginal health research.

Expressing my experience in this way may seem overly dramatic but it would take several more pages for me to explain what I believe our losses have been. To simplify what I believe we have lost in the last 2 years, I need only go back to what I shared as our successes at the last International peer review: 1. The existence of our own institute with its own Advisory board and its own strategic funding. Despite a letter to Governing Council signed by 75 Aboriginal health researchers asking GC to leave the strategic funding intact, the GC recently decided to take away 50% of each institutes allocation of strategic funding and put it into a common pool that Institutes would compete for (assuming they could find an outside partner to match funds). It now seems that this decision which would unfairly disadvantage IAPH, may be a moot point as my understanding is that the Governing Council is meeting again in a few days to vote to eliminate the 13 institute Advisory boards including the Institute of Aboriginal Peoples health as its own autonomous advisory board and merge it with other institutes. 2. The existence of an autonomous Aboriginal peer review board. This is rapidly being eliminated with the new peer review
An Open Letter

structure. 3. The capacity building tools known as the NEAHRs and AHRNET. Despite a strong recommendation from the Expert Review Team of the International CIHR review to maintain the NEAHRs and AHRNETs, they have been eliminated.

In a few short years we have seen the pillars of Aboriginal health research systematically dismantled. What we have in its place seems to be a sad substitute, such as the Pathways initiative that was launched in 2012. Instead of Aboriginal communities and researchers deciding upon the priorities as has become our practice, some mysterious source decided upon 4 priority themes to address Aboriginal health. Although problems such as tuberculosis and oral health are important, they are hardly the most pressing health concerns facing Aboriginal peoples in this country. Despite its launch in June of 2012 the first of the Pathway dollars (Stage 1 only has a total allocation of 800k) will flow to the first handful of recipients some time in 2015 -assuming they have partners to leverage with. If this story of where we are now sounds overly negative I apologize and wish that I could see it differently.

Where are we going to?

This section will be short as this part of the story has not yet been written. Next week the leadership of CIHR may decide to eliminate the Institute of Aboriginal Peoples Health Advisory as a stand-alone Advisory or it may decide not to. That is your responsibility and your decision which will be part of your legacy. Clearly I cannot look at these events objectively. I would prefer to be part of a story in which my sense of pride in CIHR is restored and in which I witness the reinstatement of what was once a respectful, reciprocal and responsible relationship with Aboriginal peoples and not part of an ongoing story in which I feel ashamed of my association with it as I do now. If Canada sincerely wishes to redress historical harms and address the ongoing harm caused by the health gap that exists between Indigenous peoples and the rest of the population then we need Aboriginal health researchers, Aboriginal communities and CIHR to work together and not in opposition to each other. Onen enska ne-io-kwa-ni-kon-ra (Now our minds are one).

Respectfully submitted,

Rod McCormick PhD
Kanienkehaka
Professor and BCIC Research Chair
Aboriginal Child and Maternal Health
Faculty of Human, Social, and Educational Development
Thompson Rivers University
Kamloops, BC, Canada V2C0C8
Dear Colleagues:

I am writing this letter to add my voice to that of other colleagues in the field of Aboriginal Health to ask that you review and reconsider the direction taken with respect to the future of the Institute of Aboriginal Peoples Health and the dedicated support that CIHR provides to research in the area of Aboriginal Health. I am writing in my capacity as Chair, Indigenous Studies, Trent University and as one of the first Science Officers of the ABH peer review committee and now its current Chair. I have seen the creation of a meaningful and relevant Aboriginal Peoples’ health research environment based upon the notion of research with Aboriginal peoples rather than research on Aboriginal peoples and the notion of research that is directed towards Aboriginal priorities. I have also seen improvement in the quality of research conducted on Aboriginal health issues. The probability that better health interventions can be developed and implemented is much increased if the research that these interventions is based upon is undertaken collaboratively with Aboriginal communities and their institutions.

I have also seen the incredible improvement in the capacity of Canadian researchers to undertake research with Aboriginal communities through the development of the NEAHR and AHRNET funding programs. These programs provided support for new researchers, students and community members to develop their capacities to conduct research and to translate the results into meaningful programs and interventions. Consistent with Aboriginal ideas about how to work together for common benefit, there is now a group of researchers who know how to collaborate with Aboriginal leaders and communities to define, conduct and report on research that is relevant to local issues and which can have national and international implications. These were and remain important concerted and focused efforts in capacity building. The CIHR, in establishing the IAPH, ensured that such an effort demonstrated Canada’s commitment to the creation of a just and healthy society.

There is much benefit to be gained from such a concerted effort and for sustaining it over a lengthy period of time. In fact, the Royal Commission on Aboriginal Peoples recommended just such an effort to improve Aboriginal economic and social conditions alongside its proposals for a new relationship between Aboriginal Peoples and Canada. Its recommendations have been largely ignored and there is
considerable evidence that social and economic conditions have not improved much over the last two decades and that health conditions have similarly not improved.

James Daschuk in *Clearing the Plains: Disease, Politics of Starvation and the Loss of Aboriginal Life* (2014) set out to ‘identify the roots of the current health disparity between the indigenous and mainstream populations in western Canada’. He argues that it was the failure of the federal government to respond adequately to the emerging famine and spread of tuberculosis that, along with other factors has led to the current health disparities. In a talk about his book in early November at Trent University, Daschuk reported that social and economic determinants of health account for 75% of the health of a population. Given the century and a half long assault (1851 to 1972) on Aboriginal lands, resource and identities by the Canadian government and the resultant social dislocation, economic deprivation and identity transformation, it is not surprising that there are such large disparities. Aboriginal peoples in Canada continue live in the shadow of racism and discrimination as the 2014 CBC Environics poll indicates. Diane Hill and Robert Antone (*The Power within People, A Community Organizing Perspective*, 1986) coined the term ‘ethnostress’ to describe the social, psychological, physical and mental effects of living in a society that constantly wants you to be something else. Much of what we see today is the result of what Hill and Antone describe as a ‘disruption of the Aboriginal Spirit.’ It will take at least two decades, and more, of dedicated multi-disciplinary concerted research effort to address health issues that have their roots in historical practices and contemporary life. It is hard to conceive of such a dedicated and focused effort being undertaken through the proposed new structures and processes.

The IAPH approach is part of the solution. It provides a site for multi-disciplinary research discussions about Aboriginal health. It brings Indigenous Knowledge to the table, grounding solutions in Indigenous understandings of the world and health and instilling pride in Indigenous knowledge and its ability to be part of the knowledges to effectively address the problems within Aboriginal communities.

This is not the time to change course or emphasis or dilute the effort. My three decade experience in organizations has led me to conclude that without a visible organizational mandate, a dedicated budget, a defined organizational structure to carry out the mandate and an executive leadership that is responsible for Aboriginal programs that Aboriginal issues are treated in a minimal fashion and are easily overshadowed by other organizational priorities. In the case of Aboriginal peoples health research, without a dedicated institute, sustained funding and organization structures, much of what has been gained will be lost very quickly. While gains have been made, these are fragile and still require nurturing and support. Without it, the research capacity that has been carefully nurtured will begin to dissipate and within another decade we will be launching another program to rebuild it.

CIHR is to be congratulated on its leadership in Aboriginal Peoples Health research as the International Review Panel found. This leadership has been grounded in the principle of a concentrated focused effort on an issue of national priority. As Duschek indicates, the roots of the issue rest in the history of the last century. It will
take more than one decade of concerted effort to change the situation. Now is now the time to dismantle the structures that are starting to produce results.

On a similar issue in education in Ontario, in 1991 I argued that if one was going to make changes in the recruitment, retention and education of Aboriginal students in post secondary education through the funding of special programs within Colleges and Universities that this effort had to be based on dedicated and stable funding over at least two decades, if not more. The Ontario government after much discussion and two evaluations agreed. The program elements may change from time to time but the commitment to dedicated and stable funding remains and is starting to produce results. Every university in Ontario now has Aboriginal student supports and Aboriginal educational programming that is developed in collaboration with local Aboriginal communities. Aboriginal students and Aboriginal issues are small components of most universities and without this leadership would have been lost amidst larger concerns.

I would urge you to reconsider how CIHR may make a similar commitment. Ten years to correct a situation that has taken a century and a half to evolve means that that this important work has just started.

With respectful greetings,

David Newhouse

David Newhouse
Chair, Indigenous Studies
To All Members of the Governing Council of the Canadian Institutes of Health Research

Chair, Dr. Alain Beaudet
Vice Chair, the Honourable Michael Wilson
With special attention to Dr. Nadine Caron

Please distribute to all members of the CIHR Governing Council.
Friday, November 14, 2014
Re: To Review policy changes to CIHR Institute of Aboriginal Peoples’ Health.

Dear Chair and Governing Council of the Canadian Institutes of Health Research;

Whereas First Nations, Inuit and Metis Peoples’ of Canada have begun to show improvements in health status and socio-economic conditions over the past several decades and part of this progress can be attributed to the creation of the Canadian Institutes of Health Research Institute of Aboriginal Peoples’ Health (CIHR-IAPH), there is little doubt that much more can and must be done to ensure that future generations of Indigenous Peoples’ of Canada attain health status that is on par with their counterpart mainstream populations.

Leading social theorists like Sir Michael Marmot and many prominent Canadian and International population health scientists have known for more than 50 years that community-based initiatives targeted at specific health and social issues and conditions, must address the underlying drivers of ill health, the so-called ‘causes of causes’ of health inequalities which are the key to tackling profound challenges in achieving lasting improvements in the health outcomes of any population. This notion has particular relevance to First Nations, Metis and Inuit Peoples’ of Canada and Indigenous Peoples’ around the world.

The challenge in Indigenous health is to achieve inter-generational well-being. This concept has been articulated in many versions of what has become an old story told in a plethora of publications likely beginning with the seminal Report of the Royal Commission on Aboriginal Peoples’ (1996), including the Kelowna Accord (2005) and in a recent 2014 report published by the Canadian Academies of Health Sciences discussing empowering strategies:

“Intergenerational well-being is important to the overall picture of Aboriginal community health and wellness...Without a factor that attends to the continuity across generations and the historical traumas and losses Aboriginal people have experienced, the contemporary realities of food insecurity and resultant poor health outcomes could not be fully articulated, nor could ideas for empowering strategies that enable people to maximize their human potential.”

1 Aboriginal Food Security in Northern Canada: An Assessment of the State of Knowledge. Canadian Academy of Health Sciences, 2014
So what does any of this have to do with the CIHR-IAPH? Well you may be pleased to know that CIHR and IAPH together have become world leaders in addressing these issues through a governance model that respects Indigenous leadership, an ethics policy that articulates community relevance and partnerships and a significant investment in future generations of scholars engaged in innovation concerning advanced indigenous health knowledge creation.

While the world looks to Canada as a global innovator it seems CIHR is advancing policies that in my view will diminish the trajectory of success and global innovation which CIHR and IAPH can rightfully take credit. Due to economies of scale Canada may never be the global leaders in other areas of health research but Canada does have a competitive leadership advantage in global Indigenous health and that should be celebrated, sustained and valued. Unfortunately, the recent policies seem to be diminishing the significant gains made since the inception of CIHR in 2000.

Rather than go into the specific program changes for which I am sure you are all well aware, I would like to point out the larger opportunities where CIHR can lead Canada and indeed the world, by showing that academic success is possible and educational achievement needs to have role models like the world class health scientists who are here and now showing the next generations of young people that success is within their reach. Pursuing of this goal has much broader economic consequences for Canada as articulated in a MacLean’s Magazine article:

‘In 2006, only eight per cent of Canadians with Aboriginal ancestry had university degrees, compared with 23 per cent of non-Aboriginal Canadians. This is not merely too bad. There is a genuine economic and human cost, because the correlation between higher education and various social goods is exhaustively documented. Post-secondary education attainment is associated with better health, increased civic participation, lower crime rates, higher income, correspondingly higher tax payments, reduced dependence on social benefits, and more.’

‘A February 2010 study by the Centre for the Study of Living Standards suggests that if the gap in educational attainment and labour-force participation between Aboriginal and non-Aboriginal Canadians vanished by 2026, total tax revenue would increase by $3.5 billion and government spending could decrease by $14.2 billion.’

Finally, I am Mohawk, a member of the Tyendinega First Nation in Ontario. From 2000 to 2008 I was the inaugural Scientific Director of the Institute of Aboriginal Peoples’ Health at the Canadian Institutes of Health Research.

My background, experience and connection to the research community provide me with a unique perspective on Aboriginal health research in Canada and Indigenous health research in other parts of the world.

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2 Source: Paul Wells <http://www2.macleans.ca/author/inklesswells/>
An Open Letter

Thank you very kindly for reviewing this unsolicited letter and please contact me directly should you require clarification or additional information.

Sincerely,

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An Open Letter to Dr. Alain Beaudet, President, the Hon. Michael Wilson, Vice-Chair of the Governing Council, and Other Members of Governing Council

Canadian Institutes of Health Research

During the first decade of its existence, CIHR seemed to have the right approach in its emerging relationships with Aboriginal people. One of the 13 institutes dealt entirely with issues of Aboriginal health; the highest priority -- to build capacity in Aboriginal health research both with respect to students and communities -- was being pursued; major advances were being made in developing appropriate protocols for research involving Aboriginal peoples; significant gains were made in the quantity and quality of research; and CIHR’s strategic plan identified the reduction of health disparities affecting Aboriginal peoples and other vulnerable populations as a system-wide priority. These things worked because they were constructed by Aboriginal people themselves, with important contributions from others within and outside CIHR, including the CIHR Presidents.

In the last three years, the approach has changed dramatically. A serious rift is now developing between CIHR and the Aboriginal health community and beyond. CIHR has only a short period of time to address the matter before the issue receives widespread attention and there is long-term damage. The divisions concern both substance and process. In the past three years, CIHR has made specific decisions and adopted specific policies that are, in my view, misguided. Secondly, the process that has been followed is also at fault. Let me begin with the substance, which involves three matters.

Issues of Substance

(1) The termination of support for capacity building for Aboriginal health research. Up until this year, CIHR has made a substantial investment in capacity building, notably by funding regionally based centres (NEAHRS) and a national network (AHRNETS) whose main function was to engage in capacity building. They did so by providing scholarships to promising students as well as other kinds of peer and mentoring support. At any one time, dozens of students were being assisted – a few at the Bachelor’s level and many more studying for Master’s and PhD degrees. Some have now obtained faculty and other research positions, and are the future of Aboriginal health research in this country. Financial and faculty support was also provided to community-driven research projects, with the NEAHRS serving as a bridge between the research community and Aboriginal communities, slowly overcoming decades of mistrust and suspicion.

There are many accounts that suggest that the NEAHRS were very successful in what they did, not least the report of CIHR’s own International Review Panel, which celebrated their achievements and
recommended that they continue. Yet, funding from CIHR has been terminated. This is not to say that the NEAHRS should have been supported forever, but we have insufficient numbers of Aboriginal health researchers in Canada and it is too early to back off from what is unavoidably a long-term undertaking. From having dozens of students in graduate programs, we now have a handful who will be successful in national competitions for scholarships. A few others will be picked up by research projects which will also attract the interest and involvement of a few communities. To its credit, IAPH continues to underwrite the National Gathering of Graduate Students and a small international mentorship program is being discussed but that’s it. It won’t be long before we are back to where we started a decade ago.

(2) Placing new obstacles in the path of research funding. CIHR has determined that research funding under the strategic grants umbrella, including such programs as Pathways, will require funding and in kind support from other sources in order to proceed. While this makes sense from the point of view of leveraging dollars, it fails to recognize that the Aboriginal health research field is not like others in that funding partners are much harder to come by. Health Canada, which has responsibility for Inuit and First Nation on reserve health funding, for the most part says that federal research dollars have to come from CIHR. Provincial health research foundations are strapped for funds and face resistance on the grounds that “Indians and lands reserved for Indians” are a federal responsibility. Aboriginal organizations, including those that would engage in health research, have either been cut altogether or their budgets have been drastically reduced. Other potential funding partners, such as companies in the resource extraction field, are often in adversarial relations with their surrounding communities for environmental and other reasons.

Open operating grants do not have this leveraging requirement, but the size of that pool has been cut almost in half in order to support the new Foundation grant scheme. The Aboriginal health community is very concerned that our field, which is not nearly as well developed as other areas of research and which has a preponderance of scholars just beginning their research careers, will be at a disadvantage in the Foundation competition. While by no means conclusive, I can relate that I have just finished serving on one of the peer review panels that is taking the first cut at the 1375 applications, and I can say that in my pool, not one deals with Aboriginal health even when the subject of the proposal has to do with the health of disadvantaged and vulnerable populations. How many applications have been submitted? How many will reach the second stage and eventually be funded?

(3) Dismantling the structures that have provided leadership for Aboriginal health research. This refers largely but not entirely to the decisions that were made at your August 2014 Governing Council meeting. We learned that the budgets of each of the Institutes will be cut in half in order to create a common pool of funds to which institutes can apply on a competitive basis. We also learned that the release of these funds will be subject to the leveraging rules mentioned above. The Institute of Aboriginal Peoples Health will lose its Advisory Board, as will the other institutes, to be replaced by a reduced number of “clustered” Boards where Aboriginal voices will be only a small minority. Ottawa-based staff will no longer be affiliated with and serving their institutes, and I suspect the role of Scientific Directors has also been eroded, with more power being exercised at the senior executive level. Finally, it appears that the new peer review processes will spell the demise of an Aboriginal-specific peer review process where persons knowledgeable about Aboriginal research and how can best be conducted are being replaced by procedures where peer review panels are mostly composed of persons without that background. This is already the case for the Foundation grant scheme and I suppose that will spread to the other competitions as well. One wonders how an Aboriginal proposal will get a fair shake under these circumstances.
An Open Letter

In my experience, this kind of homogenizing/ignoring distinctiveness approach never works when it comes to Aboriginal affairs. It didn’t work in 1969 when Aboriginal organizations reacted with outrage at the Federal Government’s White Paper that would have negated the special status of Aboriginal people in Confederation. It doesn’t work in the application of Canada’s multiculturalism policy if First Nation, Métis and Inuit people are seen as just another three tiles in the Canadian mosaic little different than myself, an immigrant from Germany. It won’t work within CIHR if their distinctive histories, cultures and needs are rolled over by system wide policies and practices.

Issues of Process

Let me turn now to the process that CIHR has followed in the last while, a process that my children would describe as one that sucks. Certainly the concerns that the Aboriginal health community has about the direction that CIHR is taking have been raised repeatedly with no discernible effect. That is not to say that no one has been listening, although that is often the impression, but if there has been an impact it is not being communicated nor are there explanations for the path taken.

With respect to the Institute Model Review, the most important player in that process seems to have been the so-called External Working Group that has proceeded in such secrecy that even now their report with recommendations has not been made available, including to CIHR’s own Scientific Directors. In looking at its composition, it is not apparent there is anyone who has any background in or sensitivity to Aboriginal health issues. Perhaps I am mistaken. Nor was there any other opportunity, it appears, for the Aboriginal health community to consider and comment on the External Working Group’s report. The CIHR web site tells us that that Institute Advisory Boards were consulted and that there were a “limited number of targeted discussions” with stakeholders. However, to the best of our knowledge, no stakeholders in the Aboriginal community were engaged, nor did the IAPH Advisory Board have any access to the analysis and recommendations produced by the External Working Group, which were, in the end, so influential. Yet Governing Council takes these recommendations, perhaps modifies them slightly, and proceeds to impose them across the board without any apparent consideration of their effects on the diversity of constituencies that CIHR is intended to serve.

In the summer, we learned about the report and about impending action by chance, a couple of weeks before Governing Council is to meet in August and make decisions, but there is no background information, only rumours. Through Jeff Reading’s leadership and in the midst of the summer vacation season, 75 of the most prominent persons in the Aboriginal health field send a letter to the President and Governing Council. Receipt of the letter is duly acknowledged, for which we are grateful, but there is no further communication – no discussion of the issues raised, no offer to meet with a delegation to discuss what might be done to address the concerns. We learned of the Governing Council’s decision a few days later on the CIHR web site and it was not good news.

In a context where the deplorable health evident in many Aboriginal communities is arguably the number one health issue facing the country, where there is widespread anguish over the fate of missing and murdered Aboriginal women, and where CIHR has made the reduction of health disparities affecting Aboriginal people one of its highest priorities, one would have thought that such a group would receive more than a public relations letter.

The process at CIHR in recent months compares quite unfavourably with the respectful engagement that SSHRC has undertaken as it reshapes how its policies and programs can better serve the Aboriginal
community, including listening closely to the wisdom provided by an Aboriginal Advisory Circle.

The Risks to CIHR

Up until now, those who have objected to decisions made by the CIHR leadership have taken on one issue at a time, but when all the decisions are laid out, as I have tried to do in this letter, it looks more like a pattern and is a more serious proposition. What are the risks that CIHR is facing if it continues along this path?

(1) People are already angry about the decisions CIHR has made and how it has made them. I suppose the good news is that, as the August letter has demonstrated, there is still a willingness to be engaged with CIHR and help it correct its course.

(2) CIHR’s reputation, already somewhat shaky now in the Aboriginal community, will decline further and it will take a long time to rebuild the trust and engagement among researchers, communities and organizations that have so laboriously been established.

(3) There is the very real possibility that people will withdraw from CIHR, that they will no longer serve on peer review committees, sit on Advisory Boards or be willing to put their names forward for the Scientific Director or Governing Council positions. The situation is similar with respect to applying for grants. I have already heard from a number of senior scholars who say they have chosen not to apply to the Pathways program, for example, because they have no hope of obtaining the required matching funds, or they perceive their chances of success are so low with respect to the Foundation Grants scheme that it isn’t worth the effort. If the CIHR leadership is considering going further down the path it has chosen, for example eliminating IAPH as a freestanding institute, it might want to stand clear of the exits as there would be a mass exodus. CIHR would be left holding a priority in Aboriginal health while the Aboriginal health community has left the building. Clearly an organization such as CIHR relies tremendously on volunteer service to get things done, and on participation from Aboriginal and other people to communicate legitimacy. CIHR will lose both, and it won’t just be Aboriginal people who vote with their feet.

(4) There is also the risk that CIHR will be accused of practicing institutional or systemic racism. This concept, referred in the United States context as institutional racism, basically means that an institution is guilty of institutional discrimination if its policies and practices are such that a group such as Aboriginal people are systematically disadvantaged in, for example, obtaining access to an institution, in qualifying for its services or in receiving equal benefits. A case could be made that several or all of the items referred to above result in unequal access or benefit – unequal access to the Foundation grants, for example, because the playing field is not level; the requirement that matching funds are needed when there is not much hope of those being available in the Aboriginal context; facing a peer review process from a panel that is not competent to fairly judge proposals in Aboriginal health research.

On a positive note, CIHR deserves great credit for the leadership it has exercised over the past 15 years in dismantling some of the systemic barriers to community engagement to improve the health of the Aboriginal population. Capacity building at regional and local levels has resulted in more students embarking on health research careers and a dramatic increase in the quantity and quality of research proposals in partnership with community personnel and agencies. Its work on the ethics of research involving Aboriginal peoples has also been groundbreaking, contributing in a major way to the
development of the Tri-Council Policy Statement on Research Ethics (2). CIHR successes have resounded internationally, a counterpoint to negative reports of Canada’s record in human rights protection in other aspects of Aboriginal relations. Now is the time to consolidate and build on gains made, not to retrench and relegate Aboriginal health to the realm of regrettable but intractable problems plaguing Canadian society.

Getting personal

Let me conclude this lengthy letter on a personal note. I have invested a lot of time in CIHR over the past decade and a half. I was part of the small group that lobbied for the creation on an Institute of Aboriginal Peoples Health in the beginning. I have played a modest role in building the ACADRE/NEAHR centres and the national network. I have served as a member and Chair of the Institute’s Advisory Board, and I think I have taken part in at least four CIHR peer review committees over the past couple of years, with a fifth one in sight for the spring of 2015. Over the last few months, I have been thinking seriously of giving up on CIHR, throwing in the towel. My wife asks me even as I’m writing this letter: “Why are you doing this? You are supposed to be retired!” Yet I have a deep sense of loyalty to CIHR grounded in its past achievements and its potential for the future. I also have a profound sense of responsibility to the younger Aboriginal and non-Aboriginal scholars whom we have nurtured, as well as to those whose potential has not yet been identified.

I hope my faith has not been misplaced, and I apologize for writing such a long letter.

Yours sincerely,

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Principal Investigator, Atlantic Aboriginal Health Research Program
14 November 2014
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You will have received a number of letters from us individually but we haven't so far communicated who we are collectively or what it is we are asking you to do.

We have formed a Steering Committee of 13 individuals co-chaired by Dr. Rod McCormick from Thompson Rivers University, formerly at UBC, and Dr. Fred Wien, Dalhousie University. Our full membership is set out below. We are a group of senior scholars in the Aboriginal health research field spanning the country (we will shortly add Inuit representation from the North). Some of us have been involved in the NEAHR network but many have not. What unites us is the fact that we have all been strongly involved in building the Aboriginal health presence within CIHR and across the country. We are unfortunately also united in our profound concern with the direction that the senior leadership at CIHR has chosen to take in recent years. You can be assured that there are many more Aboriginal and non-Aboriginal scholars, from those just starting their careers to senior university administrators, who share our concern and commitment, as well as others outside the academic environment who are rapidly becoming aware of what is happening.

You may, of course, choose to ignore us and continue along the path you have chosen. However, the right approach is to work together to restore balance in the relationship between CIHR and the Aboriginal health community, and to rebuild the trust that has been eroded over the past several years. To accomplish this, on both sides we need to be disciplined, consider our steps carefully and put in place a process that will take us to a different, more positive, place.

To halt further damage and begin the rebuilding process, we ask respectfully that you commit without qualification to two things: (1) that you make no decisions, or take any steps administratively to implement previous decisions, that would have the effect of further undermining the Aboriginal health presence within CIHR and its programs. An example would be the plan to eliminate the IAPH Advisory Board or to dismantle the Institute of Aboriginal Peoples Health. It would not be adequate nor consistent with the kind of relationship of which we speak to be offered an opportunity to participate in the implementation of decisions that you have already made – decisions that we perceive to be harmful to the Aboriginal health community and made without any meaningful involvement by that community, and (2) that you agree to participate with us in a process to address and resolve the full range of process and substantive issues that were summarized in Dr. Wien’s letter of 15 November 2014. We envisage that would involve an initial meeting with Dr. Beaudet and other CIHR representatives as appropriate to discuss and agree to an ongoing process of dialogue. We would look to Dr. Malcolm King to form a small but senior delegation to attend this initial and subsequent meetings.

We invite you to get in touch with the co-chairs whose contact information is provided below.
Steering Committee Composition

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October 30, 2014

An Open Letter to the President and Vice-Presidents of the Canadian Institutes of Health Research

Dear President Beaudet, Vice-President Aubin, Vice-President Roy, and Vice-President Perron,

Re: Governing Council’s Decisions to Redistribute 50% of the CIHR Research Budget Envelope to a Common Fund: Request for Information on Strategy for Avoiding Competition Among Institutes and Elimination of Institute staff in Ottawa

On behalf of and with the consensus from the Institute Advisory Board of the CIHR Institute of Aboriginal Peoples’ Health, I am writing to express our sincere concerns regarding Governing Council’s recent decision to restructure the financial framework of CIHR. While the overall research budget envelope of the Institutes ($111.8 million per year) has not been reduced, for which we are pleased, we are at once dismayed by the decision to pull 50% of each Institute’s budget into a “common fund aimed at multi-Institute and multidisciplinary initiatives”.

There are four key issues that arise from your debriefing notes of August 27, 2014.

1. “Governing Council made it clear that it doesn’t want the creation of this common fund to create competition among Institutes. On the contrary, the fund is meant to encourage and support inter-Institute and inter-sectorial collaboration. GC doesn’t want to end with the “have” and the “have not”.”
Given that you have already identified the possibility of actual or perceived competition among Institutes, you must know that this is going to happen unless you have concrete mechanisms in place to ensure that, at the end of the day, $55.9 million per year sees even distribution across Institutes’ priorities. At present, there has been no indication from your Office as to what those mechanisms will be and so it would be a sign of good faith that the research community is reassured with a public announcement that such mechanisms are being developed. Logically, this would require input from the Scientific Directors and Institute Advisory Boards. Aboriginal health in Canada has historically been in the “have not” category, and it is why the health status of Aboriginal peoples is abysmally lower than all other Canadians. While up until now IAPH has effectively and efficiently fully utilized the $8.6 million per year to focus on the Institute’s priorities, we are not at a point of equal let alone equitable health status for the First Nations, Inuit, and Métis Peoples of Canada. Naturally, this decision to cut that budget by 50% is alarming and without assurance in the way of transparent and explicit mechanisms to avoid competition and ending up with “haves” and “have nots”, the statement as it stands comes across like an empty promise (of which Aboriginal peoples in Canada have been on the receiving end from multiple government agencies over the decades).

2. “Any investment originating from this fund will have to be leveraged from external sources and voted on by Science Council.”

As you are undoubtedly aware, the Institute Advisory Board for IAPH has already raised concern about seeking out or accepting leveraged funds from external sources that may have perceived and actual conflict of interest with the aims, goals, principles and beliefs of Indigenous peoples. Specifically, for example, seeking external funds from industry (i.e. oil and gas, mining, pharmacy) is to ignore the upstream problems caused by those industries, which are compromising the health of First Nations, Inuit and Métis peoples and all Canadians. From our community partners’ perspectives, this is inappropriate and would effectively compel our national, regional, provincial/territorial, and local political and advocacy organizations to seek partnership through in-kind or hard funds. This is problematic for two reasons. First, these organizations are already over-burdened with requests for their time and resources, and second, these organizations have had their budgets significantly reduced. Thus, the IAPH is put at a disadvantage at the starting gate. Hence, you can appreciate why the IAPH Institute Advisory Board is alarmed about becoming a “have not” in an environment where we already know that First Nations, Inuit, and Métis peoples are, in the well-known words of health
researcher Naomi Adelson, “the embodiment of health inequity in Canada”. In your letter to the IAPH community on August 21, 2014, you indicated that Governing Council was “mindful of the IAPH community’s issues” and sensitive to “the unique set of challenges the Institute and its community are facing in building a strong and competitive research environment”. The decisions made at the Governing Council retreat in August do not appear to be reflected in your earlier sentiments.

3. “The Institute Advisory Boards are to be restructured. The new model entails reducing the number of IABs to a total of four (4), with each IAB shared among a cluster of three to four Institutes.”

Our second concern is the restructuring of IABs. The board as presently structured allows for a wide range of voices from previously marginalized communities. We agree with the international review that the direction of CIHR was working and innovative and the proposed structure weakens the success and gains made in Aboriginal health research, capacity and community engagement. Whatever action is taken, we want to ensure that a wide range of voices are heard to secure a future direction that builds on First Nations, Inuit and Métis concepts of health and wellness.

4. “Ottawa-based Institute staff (OBIS) will be integrated into the three CIHR portfolios.”

Finally, it is our concern that the loss IAPH staff in Ottawa not only eliminates the continuity of knowledge that the dedicated staff members hold ensuring that culturally relevant and appropriate decisions are made, but it also jeopardizes the trust and positive relations that these headquarters staff have made with Aboriginal Peoples over the years. We are concerned that this will result in a gap in communications, knowledge and relations in CIHR Ottawa.

We are aware that other Institute Advisory Boards are equally concerned about this reworked financial framework. We look forward to your response to our request for Information on a “Strategy for Avoiding Competition Among Institutes and supporting CIHR’s priority to...”. Since our recent board meeting we are aware that Institute Advisory Board Chairs have been asked to sit on the four working groups that presumably would design mechanisms to mitigate any potential damage the present direction as set. While we are pleased to participate, we want to emphasize our concerns about funding, changes in the IAB structures and elimination of dedicated Institute staff in Ottawa that will perpetuate the systemic historic marginalization experienced by Aboriginal Peoples.
On behalf of the CIHR-IAPH Institute Advisory Board, please accept our sincere regards,

Simon Brascoupé  
Chair  
CIHR-IAPH Institute Advisory Board  
Simon Brascoupé  
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cc. Chairs IABs
August 18, 2014

Re: Proposed policy changes for CIHR Institutes’ strategic funding allocation.

Dear Chair and members of the Governing Council, Canadian Institutes of Health Research;

We are writing because a rumor is circulating that CIHR Governing Council is considering a major change to the current funding model that would replace the equal allocation of strategic funding to each institute with a competitive process. We understand that CIHR Governing Council is meeting in August to consider recommendations that would entail substantial changes in research funding opportunities and mechanisms. In particular, we understand that CIHR has before it a proposal to drastically reduce funds available for each of the Institutes in favour of creating a larger pool of resources that could be accessed on a competitive proposal basis, which would inevitably result in unequal allocation.

If the gap in the health and well-being of future generations of Aboriginal Peoples’ in Canada is to improve then additional, not less, funding and support is required. As Canadians, we hold dear the principles of equity and social justice and health research is an opportunity to demonstrate to ourselves and to the world that we are true to our principles and support a fair and equitable distribution of resources, in particular to address profound health disparities experienced by Aboriginal Peoples’.

A competitive approach for determining which strategic initiatives are supported will not enable optimal collaborative opportunities as made explicit in the CIHR Act: “forging an integrated health research agenda across disciplines, sectors and regions that reflects the emerging health needs of Canadians and the evolution of the health system and supports health policy decision-making; encouraging interdisciplinary, integrative health research through the creation of Health Research Institutes that together pertain to all aspects of health”

It is difficult to know how to respond to this possibility since these discussions and the background work leading up to them have been shrouded in secrecy, and there has been to our knowledge no outreach to the research community. We believe the unilateral imposition of such a decision would be counterproductive to the stated goals of CIHR. We hope this is not the case, but in the event that it is being considered, the undersigned want to strongly communicate our opposition to both the process and the policy change.

If a major decision is in the offing, we wish to signal that any initiative that reduces the ability of the Institute of Aboriginal Peoples’ Health to have the resources to respond to the critical health needs of the Aboriginal population, through research capacity building and partnerships in a strategic manner, would be regarded in strongly negative terms by the Aboriginal health research community and our Aboriginal community partners. It would be seen as another step in the retrenchment of support for training and research capacity building in the Aboriginal health research field. The recent cessation of funding for the IAPH Networks Environments for Aboriginal Health Research and sun setting of the Aboriginal Health Research Network Secretariat are the most recent examples of
diminished support for Aboriginal health research capacity building.

The Governing Council should know that members of our community have worked hard over the past 14 years, from both within and outside CIHR, to create a research climate that is responsive to and supportive of the needs of Aboriginal communities. It is a field that has not fully developed. While individual researchers have shown that they can succeed in a highly competitive research environment (the open grant competitions), the field as a whole is relatively small with many younger researchers struggling to become established and with communities that are working hard to become full partners in CIHR funded projects.

Strategic funds are particularly important for IAPH. The pattern of CIHR health research funding over the years indicates the biomedical pillar has remained dominant, the clinical pillar has received increased attention, and the health services and population health pillars have remained steady. For historical reasons (colonialism, residential schools) and cultural reasons (world views emphasizing balance) as well as contemporary socio-economic factors (poverty, racism), social determinants of health are relatively more important in our field.

Partnerships are, of course, the key to sustainable programs and CIHR IAPH is actively engaged with many organizations and individuals in pursuit of new opportunities involving many important external partners and supporters. These include a plethora of Aboriginal community groups in Canada and other Aboriginal organizations across Canada and abroad, the Provincial and Territorial Governments and their health research funding agencies, the Public Health Agency of Canada, the First Nations and Inuit Health Branch of Health Canada and many others too numerous to mention here. However, it is also clear that, compared to other institutes, there are more limited opportunities that the developing Aboriginal health field has for leveraging partnership money from the corporate, charitable and government sectors. In short, IAPH is building a foundation for partnerships with strategic funding and it relies substantially on its strategic capital to leverage funds in cooperation with the other CIHR institutes. We strongly believe an environment fostering such relations will be undermined if institutes are competing with each other for core funding and this could be a major setback for growing IAPH partnership opportunities.

CIHR IAPH is a global leader in community partnerships for health research. Both of the five-year international reviews of CIHR praised the progress made by IAPH particularly concerning capacity building and the ethical application of research guidelines meant to engage communities as partners in the research enterprise. IAPH and our community partners were instrumental in drafting the CIHR Guidelines for Health Research with Aboriginal Peoples, and for Chapter nine of the Canadian Tri-council Guidelines for Research Involving Human Subjects (2010) that now constitute the national regulations of public policy. The guidelines stipulate that Aboriginal peoples need to be consulted and engaged as partners in research that involves Aboriginal communities or individuals.

The CIHR policy on ethics has focused on social justice and on respect for human dignity through ethical attention to individual and community issues. CIHR has earned the respect and trust of community leaders, government officials, and the Academy (across Canada and abroad), including colleagues and trainees; which is no small feat when the potential for disagreement and misunderstanding is often a barrier to community-institutional partnerships and progress. Supporting IAPH is foundational in the pursuit of the goals of the Roadmap to Health Equity and, over time, the
creation and support of important new partnerships in Canada and abroad to lead the world in addressing the profound health inequities experienced by Aboriginal Peoples’.

As the first author of this letter, a letter that I have asked many colleagues to co-sign, it is important for me to identify myself to the Committee and Chair so you may assess my capacity for providing a letter addressing this important concern. I am Mohawk, a member of the Tyendinega First Nation in Ontario. From 2000 to 2008 I was the inaugural Scientific Director of the Institute of Aboriginal Peoples’ Health at the Canadian Institutes of Health Research and the founding Director of the Centre for Aboriginal Health Research at the University of Victoria (2008-2012). My background, experience and connection to the research community provide me with a unique perspective on Aboriginal health research in Canada and an opportunity to reflect the voices of researchers in this field. The signatories to this letter are researchers who have engaged communities and conducted health research that is necessary to address profound Aboriginal health disparities.

Thank you very kindly for reviewing this unsolicited letter and please contact me directly should you require clarification or additional information.

Sincerely,

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(Letter signed by 75 prominent members of the Aboriginal health research community)

Co-author

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We will be known forever by the tracks we leave

(Dakota teaching)