A Global Model and National Network for Aboriginal Health Research Excellence

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Like Dr. J.A. Amyot, a pioneer in preventive medicine, the Canadian Institutes of Health Research Institute of Aboriginal Peoples' Health (CIHR-IAPH) is a pioneer in Aboriginal health research.

We are one of the 13 founding Institutes of the Canadian Institutes of Health Research. Our vision is to enhance the well-being of First Nations, Inuit and Métis people in Canada by supporting innovative research programs that are based on scientific excellence and community cooperation.[1] Our mission is to improve the health and well-being of Aboriginal people. To do this, we must build research capacity among Aboriginal communities in Canada and in indigenous communities around the world by forming alliances and partnerships in the global health research arena. Our goals are ambitious. Yet we are faced with many challenges.

THE CURRENT STATE OF INDIGENOUS PEOPLES' HEALTH

A recent report by Health Canada, Human Resources Development Canada and Indian Northern Affairs, titled *Healthy Canadians – A Federal Report on Comparable Health Indicators,* revealed some all too common dismaying trends. For example:

- Only 38% of First Nations reported very good to excellent health compared to 61% of all Canadians;
- There has been limited success in reducing the incidence of tuberculosis (TB) among First Nations, especially in Western Canada and the Territories. The TB rates are eight times higher among Aboriginal Canadians than among Canadians in general; and
- In 1999, First Nations lost almost five times as many potential years of life to accidental injuries and three times as many years to suicide.

Smoking rates are disturbingly high among Aboriginal youth. Of those aged 20 to 24 years, almost three quarters smoke. Smoking rates are twice as high for First Nations and Labrador Inuit youth, compared to their age-matched Canadian counterparts – some 62% compared to 31% respectively.[2]

The need to close the health gap is urgent. This is the health gap within Canada – the north-south gap between Aboriginal people and mainstream Canadians. Although the United Nations ranked Canada as the number one country in the world in terms of best quality of life, the World Health Organization concluded that native reserve conditions in this country are deplorable. Reserve conditions were rated near the bottom at 63, below Thailand and Mexico. Indeed the Canadian Human Rights Commission claims "the plight of native people in Canada is a national tragedy."[3]

Scientific Director for the Institute of Aboriginal Peoples' Health at the 4th Annual Amyot Lecture, November 5, 2002, Ottawa, Ontario
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The epidemic in Type 2 diabetes

Prior to the 1940s, diabetes was not present among Aboriginal people. There were physicians who actually went to the north and did blood sugar tests and were unable to demonstrate diabetes. So in a 50-year period, we've gone from no diabetes to an epidemic situation.

Canadian Aboriginal people have undergone a rapid dietary transition from traditional foods to highly processed foods, including Coca-Cola, fish and chips, fried foods and milk shakes. This rapid transition has contributed in large part to the epidemic of diabetes among Aboriginal peoples.

A 1997 regional health survey shows a rapid increase in the cases of diabetes in the mainstream population and has spurred organizations like the Canadian Diabetes Association and Health Canada to respond to this urgent problem.

If you examine the situation in First Nations females and First Nations males, it is deplorable. It is unbelievable that one out of three First Nations women between the ages of 55 and 64 has type 2 diabetes. As you know, diabetes has a high morbidity rate in terms of peripheral vascular disease causing blindness and renal failure. It is a predictor for heart disease and is a cause of death all by itself.

In the younger age categories, there is a huge difference in terms of onset of diabetes in young Aboriginal people vs. non-Aboriginal Canadians. In Aboriginal populations, type 2 diabetes can begin as early as age seven and eight years old. This is a major epidemic and we don't know whether it has actually reached its peak yet.

There is about a 20 to 30-year earlier onset of diabetes among Native people compared to their mainstream Canadian counterparts. This means that a First Nations woman at the age of 25 has a similar incidence to that of non-Aboriginal Canadians aged 55 and beyond. This is a severe problem that needs the attention of the advanced research enterprise.

Zimmet et al., reporting on the Global and Societal Implications of Diabetes,[4] suggest that changes in human behaviour and lifestyle over the last century have resulted in a dramatic increase in the incidence of diabetes worldwide. Known diabetics are an under-estimation of the true prevalence because statistics identify individuals in the medical care system. It is like

the tip of the iceberg with a great number of unreported cases, people who haven't found out whether they're diabetic yet, and of course there are those with impaired glucose tolerance (IGT). So there's a greater number of persons at high risk for diabetes, probably as much as two thirds more than the identified rates in certain populations. This really means that for the most part, First Nations and Inuit adults living in their home communities could be considered to be at extremely high risk for diabetes.

The 'thrifty gene hypothesis' states that Aboriginal people are traditionally part of a hunter-gatherer society who evolved to survive the challenge of feast and famine. Metabolically, this means that indigenous peoples can physiologically store fat better. But in an environment of poverty, and highly processed foods with low nutrient value, this increased ability to store fat becomes a liability. Obesity is a major problem. Around the world, diabetes is a common health problem in minority indigenous populations living in developed countries. So it seems unlikely that populations so diverse and geographically dispersed around the globe could share a common genetic trait that would predispose to diabetes. This issue needs more research and could be an exciting opportunity to engage the basic biomedical research community in unravelling a very complex problem affecting a great number of people, not only in Canada but around the world.

We can start to unravel some of the linkages or causes of diabetes by looking at the environment. We think that high birthweight as well as inadequate nutrition and poverty during early life are key determinants in diabetes. This, combined with a sedentary lifestyle, dietary factors and poverty in adult life, all predispose to diabetes. Many indigenous people in Canada and around the world live in dire poverty, which in turn contributes to poor health.

INTERNATIONAL PARTNERSHIPS

Building partnerships with international organizations involved in indigenous health research has been a priority for the CIHR Institute of Aboriginal Peoples' Health since the year 2000. Why? Because health disparities between Aboriginal people and the general population in Canada are strikingly similar to those experienced by indigenous people around the world. In other words, there are similarities in the health indicators among Australian Aborigines, Native Americans, Aboriginal Canadians, New Zealand Maoris and the indigenous people of the circumpolar nations of the north. For example, Aboriginal people from the Northern Territory of Australia have a similar problem with Type 2 diabetes.

The Australian research community has initiated research to investigate indigenous people to unravel some of the complex interactions. We think it's extremely important to learn from our Australian colleagues and those in other parts of the world because these are difficult issues and we think that Canada can play a huge leadership role. In fact, if you look at our history, we have played that leadership role in the past and I think we need to continue the tradition.

The ambition of the CIHR's Institute of Aboriginal Peoples' Health is to assume a leadership role abroad. Canada can learn much from research conducted outside its borders and to this end, we have contacted several Aboriginal health research organizations around the world, and have achieved impressive results. Here are some of our key achievements.

Australia and New Zealand

A precedent-setting memorandum of understanding was signed in April 2002 by the Chief Executive Officers of CIHR and the National Health and Medical Research Council of Australia and the Health Research Council of New Zealand to cooperate on health research for indigenous populations.

The preamble of the agreement says that the national health research funding agencies realize that indigenous people want research undertaken on their own terms. The three nations are developing a more coordinated approach to improve health of indigenous populations and paying special attention to the social, environmental and economic determinants of health.

Mexico

The needs of indigenous people, and vulnerable populations are areas of potential collaboration with Mexico. Recently, a Mexican delegation of researchers visited Ottawa, and this visit further cemented the relations between Canada and Mexico.

In January 2002, the Health Secretariat of the United Mexican States and the CIHR signed a letter of intent to develop health research programs, research training, clinical training and knowledge translation based on reciprocity and mutual benefit.

United States

In May 2002, a memorandum of understanding was signed to raise the health status of First Nations and Inuit people in Canada, and the American Indians and Alaskan Natives in the United States.[5] The effort highlights our mutual intent to share knowledge and learning experiences, which will strengthen our respective approaches to improving Aboriginal health.

Circumpolar nations

Another key element of our international strategy is to form alliances with circumpolar nations. Since the inception of CIHR - Institute of Aboriginal Peoples' Health, Canada has been involved in and organizing health research meetings involving the international union of circumpolar health. We participated in a conference earlier this year [2001] in Copenhagen to learn more about the negative health conditions and barriers faced by indigenous people living in Alaska, Russia, the Scandinavian nations, Iceland, Greenland and Denmark, which are similar to those experienced by Aboriginal people living in Canada's north.

International forum

In addition, with Aboriginal researcher Dr. Judy Bartlett, we are planning the first ever International Forum on Indigenous Health Research. It will include indigenous and non-indigenous researchers and policy experts from four countries.

The forum will examine knowledge translation which is defined by CIHR as:

> *"...the exchange, synthesis and ethically sound application of knowledge – within a complex system of interactions among researchers and users – to accelerate the capture of benefits of research for Canadians through improved health, more effective health services and a strengthened health care system."*

To me, knowledge translation means using health research findings instead of

putting them on a shelf. It means engaging in evidence-based planning. And when you're working in this field, you have to ask yourself the question: Why is it that Aboriginal people are given a set amount of money to undertake their health services delivery, while the mainstream system seems to be based on addressing the problems or an evidence-based approach? I believe that this knowledge translation will give us an opportunity to go to more of a needs-based approach to creating health services and disease prevention strategies in Aboriginal communities.

An indigenous global health research network

Dr. Bartlett is also working diligently with health researchers from Australia, New Zealand, the United States and Mexico, seeking creative ways to sustain Aboriginal collaboration among health researchers on a regular basis – not just meeting every two years at a special forum. Building a virtual, indigenous, global health research network is one option that is being considered to maintain strong links.

Global Health Research Initiative

In addition, the CIHR Institute of Aboriginal Peoples' Health is excited to be involved in a research effort called the Global Health Research Initiative (GHRI). The GHRI refers to a Memorandum of Understanding among CIHR, the International Development Research Centre (IDRC), the Canadian International Development Agency (CIDA) and Health Canada, to strengthen and build capacity for global health research* in Canada and in developing countries, and to strengthen the effectiveness of overseas development assistance. To accomplish its mission, the GHRI partners work in collaboration with the members of the ever-growing Coalition for Global Health Research-Canada (CGHRC) and their friends in community-based organizations, non-governmental organizations, and governments (including agencies and departments) in the developed and developing world. Under GHRI, CIHR's Institute of Population and Public Health's Scientific Director, Dr. John Frank, led in the development and launch of the Global Health Research Program Development and Planning Grant Program. We contributed to this far-reaching and cross-cutting program, along with seven other Institutes including Public and Population Health, Circulatory and Respiratory Health, Gender and Health, Infection and Immunity, Neurosciences, Mental Health and Addiction, and Nutrition, Metabolism and Diabetes.

I have been invited to go to Africa along with some of my CIHR colleagues to attend the Global Forum on Health Research to address the 10/90 gap in which less than 10% of global health spending by both public and private sectors is devoted to 90% of the world's health problems.

The global network of indigenous health researchers is growing rapidly, thanks in large part to Canada's push on this front. With CIHR support and the expert advice from my Institute Advisory Board and staff, our accomplishments and program goals are nothing less than remarkable.

* A balanced global health research agenda focuses not only on the global burden of disease but also on the social, political, environmental and economic contexts within which these diseases occur. Assessment of Inherently Global Health Issues (IGHIs) can help complement a focus on specific diseases or vulnerable groups of the populations. The following IGHIs have been suggested as priorities for future global health research: environmental global degradation (e.g., climate change, biodiversity loss, water shortage and pollution), social/economic issues (e.g., poverty, taxation), and cross-cutting issues (e.g., food (in)security, trade of harmful products such as tobacco, illicit drugs and weapons; governance, war and conflict, gender inequities).

NATIONAL INITIATIVES

Now that I have laid out the global and international health scene and described the work that we've done in just less than two years, I think it is important to show you what we are doing at a national level. But first let me describe some of the high-level support we have been given to do our work.

The CIHR Institute of Aboriginal Peoples' Health was given a strong vote of confidence by Senator Michael Kirby and the Senate Committee on Social Affairs, Science and Technology.[6] Volume Six of the Committee's final report says:

> *"That the Committee believes that research is perhaps the most important element that will help improve the health status of Aboriginal Canadians.*
>
> *In our view, the creation of the CIHR Institute of Aboriginal Peoples' Health is an important step in this direction."*

Aboriginal Capacity and Developmental Research Environments (ACADRE)

This is the flagship initiative of the Canadian Institutes of Health Research Institute of Aboriginal Peoples' Health which we call the ACADRE for short. It is a network of networks; the key here is to focus on the environment where research can take place.

Dr. Malcolm King, a status Indian and CIHR Governing Council Member, is deeply involved.

Aboriginal health researchers from across Canada are affiliated with the CIHR Institute of Aboriginal Peoples' Health. They have made significant progress in less than two years with respect to advancing our four key priorities, which are:

- Developing and nurturing health research partnerships;
- Influencing policy development on ethical standards peer review and knowledge translation systems that respect Aboriginal values and cultures;
- Building Aboriginal health research capacity, about which I'm going to speak specifically; and
- Funding initiatives that address urgent and emergent health concerns affecting Aboriginal people.

The ACADRE program has a major focus on developing advanced research capacity to support young Aboriginal health research investigators. The ACADRE centres will provide:

- An appropriate environment and resources to encourage Aboriginal students to participate in health careers in Aboriginal health research;
- An appropriate environment for scientists across the four themes or pillars of CIHR to pursue research opportunities in partnership with Aboriginal communities;
- Opportunities for Aboriginal communities and organizations to identify important health research objectives in collaboration with Aboriginal health researchers; and finally
- Appropriate communication and dissemination strategies to facilitate the uptake of research results.

On October 11, 2001, four full ACADRE centre awards for Alberta, Saskatchewan, Manitoba and Ontario were announced.

Four more university-based ACADRE centres were added to the network in October 2002 in British Columbia, Ontario, Quebec and Nova Scotia. So, in a short period of time, we have contributed up to $25 million to a national network of research centres engaging advanced research enterprise in Aboriginal health research.

Now there are eight ACADRE centres, which represent an emerging team of advanced research environments that will focus on:

- Population health and determinants of health;
- Women's health and child health development;
- Ethics and conducting human research, community healing and health care under Aboriginal self-government;
- Prevention and control of chronic diseases;
- Addictions in mental health; and, of course
- Environment and health.

It is necessary that these centres be sustained to develop an advanced research agenda in Aboriginal health. They need to become places where investigators create excitement and the passion for doing Aboriginal health research. I think that we can achieve that in Canada. They will be sustained by grants and other kinds of funding, obtained through partnerships within our borders, but also from other agency and foundation funding from outside Canada.

Sixty percent of all these ACADRE funds must go to supporting graduate students engaged in research. Under the guidance and instruction of the CIHR Institute of Aboriginal Peoples' Health and its national network of centres, a new generation of Aboriginal health researchers is emerging who are keenly aware of the need to follow ethical research standards.

Dr. Marlene Brant-Castellano, a respected Mohawk elder and one of the leading Aboriginal health researchers and policy experts in Canada, explains that "research that reinforces powerlessness is basically harmful to health." Our agenda fully supports her sage advice.

Health Canada

Together, we are developing a work plan in partnership with Health Canada and colleagues in the United States. We envision several joint activities to advance Aboriginal health research in both countries, including:

- Sharing information on the tele-medicine and tele-health capabilities of both nations;
- Collaborating on studies of chronic diseases that have high prevalence rates in indigenous populations;
- Cooperating on strategies to support indigenous populations in the hemisphere;
- Providing guidance in working with universities and other non-governmental organizations; and
- Sharing information on health reform and innovative approaches to health care delivery.

Links with other institutes

CIHR promotes research across institutes. Not only have we done this for the Global Health Research Initiative, but for national initiatives as well.

Advanced research in Aboriginal communities will complement the CIHR Initiative on Rural and Northern Health Research, led by the CIHR-IAPH and working with Dr. Renee Lyons of Dalhousie University. The other strikingly similar initiative is the CIHR Environment and Health Research Initiative led by Dr. John Challis, Scientific Director of the CIHR Institute for Human Development, Child and Youth Health.

Native youth and smoking

My research team conducted an Aboriginal Youth Lifestyle Survey this past summer at the North American Indigenous Games held in Winnipeg, Manitoba. The Games were a unique opportunity to examine healthy, Aboriginal youth and what makes them so, as some 6,500 Aboriginal youth from all over North America participated in the Games.

It is important to focus on health and well-being in Aboriginal communities. In the past and continuing to the present day, Aboriginal people are often characterized as sick and disorganized, which reinforces unequal power relationships and, in part, undermines their legitimate aspirations for self-determination. So this study attempts to show Aboriginal youth in a more positive way, in a more positive environment, like the Indigenous Games.

In our study, we compared smoking rates among youth involved in the Games and we characterized them as either participating in the athletics events or not. The proportion of smokers among youth classified as athletes was significantly lower than for non-athletes. Also, Aboriginal youth involved in athletics were twice as likely to have quit smoking than their non-athletic native counterparts. Simply put, athletic youth were much less likely to be smokers than their non-active peers in any of the age categories that we measured.

These preliminary results indicate that there may be a very important health promotion and disease prevention potential intervention that should be considered as a significant health investment. Athletics is not a panacea for the health problems of every community. However, these preliminary results intuitively reinforce the idea that involvement in physical activity, recreation and leisure may have a significant health protection effect. Avoidance of smoking can lead to profound effects on future health and well-being.

FUTURE CHALLENGES

In combination with the unfavourable health trends I have described, Aboriginal health poses some unique challenges. The geographic reality of Canada makes it difficult to reach Aboriginal communities. There are more than 630 First Nations communities, in addition to Inuit and Métis communities spread across ten provinces and three territories.

However, technology is beginning to bridge the divide, making communication and transportation faster, which facilitates delivery of our health research programs.

Each Aboriginal community is unique with its own set of traditions, issues, values and ways of healing. Contrary to some popular misconceptions, Aboriginal people are not all the same and cannot be lumped into one category. There is no panacea that will improve health. We must consult with individual communities and respect their ways. Our challenge is to ensure that together, we find solutions that work.

To reach the goal of improved health, Aboriginal people adhere to research prin-

ciples of data ownership, control, access and possession. These are the capacities that we feel are important to an overall system of Aboriginal health information management. Developing these clear objectives and partnership strategies with specific lines of action is key to moving forward the Aboriginal health infostructure.

Many communities and individuals complain that they have been "researched to death" and they are very reluctant to participate in further projects by outsiders. We are determined to change these attitudes by working in full partnership with Aboriginal groups. We need to develop research capacity to avoid the rhetoric and begin to engage in meaningful partnerships with communities. We are determined to honour and balance the Aboriginal world with the scientific and academic worlds.

CONCLUSION

As the Institute's inaugural Scientific Director, I have the distinct privilege to be working with an amazing group of committed researchers whose aim is to improve the health of indigenous peoples from all around the globe. I hope I have presented a clear picture and a brief introduction to the CIHR Institute of Aboriginal Peoples' Health.

I have told you of our goal to be a world leader and have explained our approach to forming international partnerships and the rationale behind this activity. As for our national agenda, we have developed a sound foundation upon which to practice and promote what we think is world-class Aboriginal health research. By following these priorities, we are determined to reduce health disparities between Aboriginal communities and mainstream Canada through evidence-based research that respects Aboriginal cultures.

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Thank you also to Mr. Ian Potter, Assistant Deputy of Minister of Health and a member of our Institute Advisory Board, who was instrumental in bringing together parties to sign the historic Canada and USA agreement on indigenous health cooperation. Thanks to Dr. Judy Bartlett, an Aboriginal researcher based at the University of Manitoba and a member of our Advisory Board, who is actively engaged with colleagues at home and from around the world.

Finally, I'd like to give special acknowledgement to the following individuals: the CIHR-IAPH Institute Advisory Board, led by the Chair, Dr. John O'Neil, Professor and Head of Community Health Sciences and Director of the Center for Aboriginal Health Research at the University of Manitoba; Ms. Laura Commanda, who we recently recruited to join as our Ottawa-based research project manager; Ms. Linda Day, who we were able to attract from the Summit Chiefs of British Columbia, and who is now based at the University of Toronto as our research projects manager; Trudy Jacobs, our secretary; Mr. Earl Nowgesic, assistant director of the institute, who we recruited from the Assembly of First Nations to come over and join us at the University of Toronto – he is also an assistant professor in the department of public health sciences; Ms. Alita Perry, the Ottawa-based manager of the Global Health Research Initiative; Ms. Jennie Piekos and Ms. Sittanur Shoush, consultants based in Toronto and Edmonton, respectively; and finally, Ms. Ginette Thomas, the Ottawa-based manager of the Rural and Northern Health Research Initiative, and the former IAPH institute liaison.

REFERENCES

1. Reading J, Nowgesic E. Improving the Health of Future Generations: The Canadian Institutes of Health Research Institute of Aboriginal Peoples' Health. *Am J Public Health* 2002;92(9):1396-400.
2. Reading J. The Tobacco Report. National Steering Committee of the First Nations and Inuit Regional Health Survey. 1999;87-135. ISBN 0-9685388-0-0.
3. Toronto Star Editorial; April 30, 2000;A12.
4. Zimmet P, Alberti KGMM, Shaw J. Global and societal implications of the diabetes epidemic. *Nature* 2001;414:782-87.
5. Secretary Thompson signs agreement with Canada on indigenous health during 55th World Health Assembly. Geneva, Switzerland. May 14, 2002. Available on-line at: http://www.turtleisland.org.
6. The Health of Canadians. The Federal Role. Final Report Volume Six. The Standing Senate Committee on Social Affairs, Science and Technology, October 2002.