

# A New Approach to Health Research in Canada's North

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## ABSTRACT

Over the past four years, despite low resource allocations to the North, northern residents and community organizations have taken significant initiatives towards the development of health research. In this commentary, we present a model for the development of northern health research based on our experiences in establishing the Institute for Circumpolar Health Research (ICHR) in the Northwest Territories. It is hoped that the lessons we have learned will inform decision-makers and encourage them to make strategic investments to support further health research capacity and institutional development within the North. Factors that have enabled the development of a health research institute in the North include leadership, a vision for health research, and the engagement of key partners and stakeholders. Challenges arise in the development of appropriate governance and policy for health research. There is an urgency to target resources to support the development of policies and governance for health research in northern jurisdictions. Both academic and community-based research need to be strengthened.

**Key words:** Research; health policy; arctic regions; public health

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Over the past 20 years, there have been a number of reports on supporting and developing northern health research.<sup>1-5</sup> These all reached similar conclusions, calling for increased infrastructure and capacity for health research, involvement of northerners, and recognition of various knowledge bases present in the North. Such consultations continue as little progress has been made towards redressing the north-south disparity in health research.

Despite low resource allocations to the North, northern residents and community organizations have taken significant initiatives towards the development of health research. In this commentary, we present a model for the development of northern health research based on our experiences in establishing the Institute for Circumpolar Health Research (ICHR) in the Northwest Territories. It is hoped that the lessons we have learned will inform decision-makers and encourage them to make strategic investments to support further health research capacity and institutional development within the North.

Originally incorporated under the NWT Societies Act in 2005 as the Arctic Health Research Network Northwest Territories (AHRN NT), AHRN NT changed its name to ICHR in 2009 to reflect more accurately its mandate to conduct research, facilitate research, and engage in research training, knowledge synthesis and dissemination. In the short span of three and a half years, the Institute has obtained \$4.7 million in grants and contracts to support various research activities.

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### Leadership and partnerships

The ICHR board of directors adopted as its vision statement, *"Building on the strengths and knowledge of all cultures to achieve health"*. We

have stayed away from governance models where board members are composed of representatives of stakeholder organizations, as it increases the potential for conflicts of interest when board members have mixed mandates and feel the need to advance the interests of the "parent" organization rather than those of the Institute. Instead the Institute board consists of individuals who bring various perspectives and experiences to ensure that the Director upholds the vision and mandate of the Institute.

On a project-by-project basis, ICHR enlists a broad base of partners, who do not play a role in the governance of the Institute. These partners are engaged because the research area has particular relevance to their organization. Partners to date have included Indigenous governments, policy-makers, health care providers, and community organizations. The partners provide guidance on research priorities and are involved in project implementation and interpretation of research findings. Such a partnership model thrives within a northern culture of consensus and close-knit communities and organizations.

The partnership approach of ICHR enhances evidence-based practice in support of policy development, clinical decision-making and health system design by incorporating the inputs of various partners. The output of the research is a synthesis of various knowledge sources and perspectives. Relevance is built in at an early stage, as are economic and political considerations that will influence the course and outcome of a research project.

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**Research program**

The Institute board, staff, and advisors have identified five research themes for development. These themes were selected for their strategic advantage because of the physical location in the North and likelihood for long-term sustainability. They also reflect current capacity and the availability of northern-based researchers to serve as group leaders.

*Research Themes*

- Developing youth-driven community-based participatory methods
- Improving health systems performance
- Monitoring changing population health status
- Understanding socio-economic determinants of health
- Assessing the impacts of health research.

The Institute appoints senior research fellows from universities across Canada and also in other circumpolar countries who will participate in these research programs and mentor our northern-based researchers. Representatives of northern communities, governments, and health care institutions will also participate in program design and partner on individual projects. The Institute director will also draw upon the strategic advice of an international scientific advisory council.

**Governance and policies**

Historically, northern-based researchers have often conducted research as independent scholars or consultants or within NGOs as there are not any university structures to work from. They are dependent on guidelines provided by funding agencies, government regulations and community organizations. As a result, policies that oversee northern-based health research are fragmented and usually vary from project to project.

Generally, research funds are disbursed to and administered by universities and affiliated research institutes, which have long-established policies and structures to ensure accountability and quality. Thus it is not surprising that territorial institutions without university affiliation do not meet criteria to access these funds for health research.

Some northern institutions have taken small first steps. For example, Yukon College has acquired the status to be eligible for receiving and administering SSHRC funds. Memorial University of Newfoundland has established a tenure track position in health research at the Labrador Institute located in Goose Bay. Two senior staff members of the Institute for Circumpolar Health Research have recently received off-campus, status-only faculty appointment at the Dalla Lana School of Public Health, University of Toronto. Such small steps are essential to building northern-based research capacity. The day when a northern-based researcher can apply for and be successful in receiving a tri-council research grant will be a tangible marker of advances in capacity building for health research in the North.

Barriers exist within our northern institutions to support and promote excellence in academic and community-based research. Foremost is the lack of policies similar to those which uphold health research practices in university structures. ICHR has developed memorandums of understanding with university researchers on a project-by-project basis. While this process meets the immediate needs for health research in the territories, it does not promote long-term sustainable health research in the North.

Ultimately, a formal affiliation agreement with a university will allow the Institute to build its research programs, hold tri-council grants, supervise northern-based graduate students and offer graduate-level courses in the North.

Further work is also required to develop policies and frameworks to support community-based research. Research funding targeted at community-based initiatives is becoming more common and in many instances university partnerships are not required. However, in many cases community-based organizations struggle with meeting requirements laid down by licensing bodies and funding agencies, creating additional challenges for already under-resourced research partners.

**Ethical oversight**

In the northern territories, all research – including health research – is governed by a scientist's act. This act ensures a process of regional consultation and an obligation to register and report back on research activities. Health Research Ethics Boards (HREB) also play a role in overseeing research practice. In the North there are few functional HREBs, and these are highly variable in their structure and capabilities. There are immediate needs to coordinate, streamline, and enhance the capacity for health research ethics review in the territories. These efforts must occur in tandem with the development of health research institutes.

Policies and procedures related to ethical review that have been designed for university-based researchers have the unintended illogical result that community organizations that apply for research funding often have to demonstrate community relevance and provide evidence of community consultation and community approval.

**Northern consultations**

The federal government has developed a national science and technology strategy.<sup>6</sup> While this document offers clear and strategic directions for research, the underdevelopment of health research in the North prevented northerners and their institutions from contributing to, benefiting from, or responding to such strategies.

To their credit, national research agencies have not neglected the North – witness the parade of northern consultations that have passed through the North in recent years. But northern input is often sought after strategies have been set and resources have already been allocated. Northerners have resorted to political channels to evoke timely change or access resources for research programs, a practice that is neither strategic nor beneficial as advances for the North are made in a reactive rather than proactive manner. So, while northern consultations are required to enable national organizations to better serve northern jurisdictions, it must be stressed that the consulting organizations need also to explore their own policies and governance structures to determine why northern stakeholders engaged in health research are not at the table from the outset.

**Research funding**

A quick scan of the millions of dollars in funding allocations of the tri-council bodies (CIHR, SSHRC and NSERC), the Network of Centres of Excellence, Canada Research Chairs and the Canada Foundation for Innovation programs reveals the complete lack of a primary grant holder from the northern territories. In 2007,

of \$6.3 billion spent on health research systems in Canada,<sup>7</sup> none flowed directly to a territorial jurisdiction. Thus, while all the national programs are well positioned strategically to support excellence in northern health research, they currently fail to address immediate capacity needs in the North itself.

As a northern-based entity, ICHR has by necessity sought alternative mechanisms and methods to fund and support its health research activities. Due to good timing and visionary partners who have demonstrated a true commitment to northern-based research capacity, ICHR was able to access some stable funds for three- to five-year periods. These supporters include the federal International Polar Year (IPY) program, the CIHR Team in Circumpolar Health Research led by the University of Toronto's Dalla Lana School of Public Health, and the Government of the Northwest Territories through the Tri Territorial Health Access Fund. Most recently, ICHR was the only health research organization in the North to receive funding from the Arctic Research Infrastructure Fund, which enables it to develop research space in close proximity to the regional health and social services authority in Yellowknife.

In each of these instances, it was the leadership within the funding agency who recognized the barriers and struggles for northern access to research funds. Adjustments were made so that allocations can be made to northern organizations engaged in health research. The federal IPY program in particular moved the agenda forward for northern-based health research and made special efforts to support both academic and community-based researchers.

As a young organization, ICHR had to be constantly alert to funding opportunities and respond in a timely fashion. To sustain a small research institute, approximately \$1.5 million in contracts and grants are required each year to cover the indirect costs of research and core operations. Since 2005, such costs have been recovered from a total of 22 contribution agreements and grants. The time dedicated to the administration of these grants has been substantial and detracts from the research mandate of the Institute. Each grant is associated with its own proposal writing, contract negotiation, periodic reporting, and financial audits. Northern-based researchers are at a clear disadvantage to their provincial and university-based colleagues as they lack institutional support for such functions. Immediate solutions are required to rectify this situation, as current practices are not conducive to advancing a science agenda based in the North.

### Research impacts

Inspired by the assessment undertaken by the Canadian Academy of Health Sciences,<sup>8</sup> ICHR recognizes the need to measure and monitor the impact of research and returns on investment in the North, including advancing knowledge, informing decision-making and gains in health outcomes.

Specific attention will be required to measure capacity building for health research, as we move academic research into northern jurisdictions. Measures of capacity need to capture activities in a broad cross-section of organizations which do not necessarily have research mandates. In evaluating the impact of research, a distinction needs to be made between conducting research and facilitating research. In facilitating research, northern stakeholders contribute to proposal development, serve on steering committees, and assist with data access and dissemination. It is important to recognize when a project is led or directed by a northern stakeholder.

As comparable frameworks are developed and put in place, northern-based academic and community research activities can then be compared nationally and internationally. ICHR is well positioned to create and adapt impact models and measures for the northern research environment.

### CONCLUSIONS

The interaction of various factors has contributed to the establishment of the Institute for Circumpolar Health Research in the Northwest Territories. Committed individuals in the North have demonstrated the ability to set a vision and mandate for northern-based health research, bring together partners, and develop teams to support research programs that have relevance regionally, nationally and internationally. There is an urgency to target resources to support the development of policies and governance for health research in northern jurisdictions. Both academic and community-based research need to be strengthened.

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### RÉSUMÉ

Au cours des quatre dernières années, malgré le manque de ressources attribuées aux régions nordiques, les résidents et les organismes communautaires du Nord ont lancé d'importantes initiatives pour développer la recherche en santé. Dans ce commentaire, nous présentons un modèle pour le développement de la recherche en santé nordique d'après notre expérience de l'établissement de l'Institute for Circumpolar Health Research (ICHR) dans les Territoires du Nord-Ouest. Nous espérons que les leçons de cette expérience seront utiles aux décideurs et les inciteront à faire des investissements stratégiques pour rehausser la capacité de recherche en santé et le développement institutionnel dans le Nord. Les facteurs qui ont permis la création d'un établissement de recherche en santé dans le Nord sont le leadership, une vision de la recherche en santé et la mobilisation des partenaires clés et des parties prenantes. L'élaboration de structures décisionnelles et de politiques adaptées à la recherche en santé présente des défis. Il est urgent de cibler les ressources qui appuieront l'élaboration de ces politiques et de ces structures dans les territoires nordiques. Il faut renforcer à la fois la recherche universitaire et la recherche communautaire.

**Mots clés :** recherche; politique sanitaire; arctique; santé publique