

Rural Health Research in the Rural Health Research in the Canadian Institutes of Health Research

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by

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Rural Canada is about 20% of the employed Canadian workforce, one third of the Canadian population and over 90% of the nation's territory. It is a highly diverse economy and society, from its coastal regions, through its remote areas and its agrarian heartland. Rural Canada provides employment, forest products, minerals, oil and gas, manufactured goods, food security, and foreign exchange. It processes metropolitan pollution, educates a third of Canada's youth, and manages the environment on behalf of all Canadians. Rural Canada provides recreation and countryside amenities for all Canadians.

Introduction

The inauguration of the Canadian Institutes of Health Research (CIHR) on April 1, 2000 will usher in a new era in health research in Canada. Not only will there be more resources to support and expand health research, there will also be a new way of thinking about health research and its roles. More specifically, the CIHR is interested in supporting health research that integrates different disciplines and research sectors, that is of high calibre and that can contribute to improving the health and well-being of Canadians. Undoubtedly, the CIHR will have some difficult decisions to make. In particular, it will have to decide what kinds of health research it will support and in what form.

The Centre for Rural and Northern Health Research at Laurentian University and Lakehead University, in collaboration with the University of Northern British Columbia, has been commissioned by the Canadian Health Services Research Foundation and the Social Sciences and Humanities Research Council to prepare a position paper, the purpose of which is to examine the role of rural health research in the CIHR and how the CIHR can support rural health research in this country. This is one of about 20 position papers on various aspects of health research commissioned by the Canadian Health Services Research Foundation and the Social Sciences and Humanities Research Council.

In the following sections, we explain what rural Canada is and why rural health research is important and needs to be supported by the CIHR. We believe there are good reasons to regard rural health as a distinct area of enquiry that requires dedicated attention and resources, best achieved through a separate institute. At the same time, we realize that rural health research, as an integrative and well coordinated research enterprise, involving many disciplines, linking the four sectors of research and bridging basic and applied research, is a fairly new venture. Thus, we propose a series of strategies and steps to develop and support a new way of doing rural health research under the CIHR. Furthermore, realizing that a stand-alone Institute for Rural Health Research may not be feasible at this time due to many competing demands, we discuss some alternative approaches that the CIHR Interim Governing Council may wish to consider.

Although this position paper is prepared by the Centre for Rural and Northern Health Research, in collaboration with the University of Northern British Columbia, it is not about any particular research

centre, academic program or university. Instead, we strive to speak on behalf of the rural health research community in Canada. As part of the research process, members of the research team contacted many individuals throughout the country and in selected foreign countries, who were experts in rural health and/or rural health research. A list of the individuals contacted or consulted in relation to this project can be found in Appendix 2. Because of the very short period of time in which we had to complete the project and because the study was conducted over the summer months, it was not possible for us to contact more people. However, we believe we have spoken to a reasonably representative group of individuals who are extremely knowledgeable about rural health and/or rural health research issues. This position paper has benefitted greatly from their input and interest.

Rural Canada

In terms of area, rural Canada accounts for over 90 percent of the land mass of the country. From about a quarter to about a third of the Canadian population can be considered rural, depending on whether the Statistics Canada definition or the OECD definition is used (Pitblado et al., 1999). In other words, as many as 10 million Canadians are rural residents.

Like "health", "rural" is not a cut-and-dried concept. There are many definitions and no one is universally accepted. Some people think that the official definitions are too restrictive. For instance, while agreeing that the Statistics Canada definition of rural is useful, the National Liberal Rural Caucus (1999) maintains that communities with more than 10,000 people should be considered rural if their economic foundation is based on primary production and processing activities, rural culture or nature tourism. Others believe that some remotely located cities, which do not fit the official definition of rural, are actually more like rural communities in terms of geographic isolation, economic and labour force characteristics and availability of services and amenities. If such more liberal notions of rural are adopted, the proportion of the Canadian population that can be classified as rural will be considerably larger. In this policy paper, the term "rural" is used in a short-hand way to include regions, communities or populations that are sometimes called "small town", "northern" or "remote".

Rural Health and Rural Health Research

It is not just the size of the rural population that is important from the perspective of health research. Equally important is the fact that rural Canada has many serious and protracted health problems that need to be better understood and resolved with the help of research. Although there is a lingering idyllic notion about the countryside and rural lifestyle and a lot of talk about a rural renaissance, in reality,

many rural communities in Canada are facing demographic, ecological, economic and social challenges due to geographic and social isolation, depletion of natural resources, boom-and-bust cycles in primary industries, chronic high unemployment, out-migration of the young, population aging, environmental decay, inadequate or deteriorating municipal infrastructure, etc. These problems have profound implications for the health and well-being of rural Canada.

On the basis of data from the Quebec Health Survey, Robert Pampalon has noted "a trend towards a progressive deterioration in health as one moves from that area bordering urban centres into the very remote hinterland" (Pampalon, 1991). Such a worrisome picture can be used to depict many other rural regions in the country. Much higher prevalence of heart disease in northern Ontario; higher prevalence of certain types of cancer among miners and farmers; substantially higher rates of diabetes, respiratory and infectious diseases, as well as violence-related deaths, in some aboriginal communities; and higher infant mortality in some rural areas are just a few examples. Residents in small rural communities also tend to have shorter life expectancy and higher rates of long-term disability and chronic illness. Agriculture has been identified as one of the most hazardous occupations. Other predominantly rural-based economic activities such as mining, forestry and fishing are not far behind in terms of health risk. Rural health hazards do not affect just the rural population. For instance, antibiotic use in farming and its contribution to resistant bacteria is a potential health problem that can affect all Canadians.

In addition, there are major problems in rural health care delivery. The chronic and often critical shortages of physicians, rehabilitation therapists and other health care providers are well-known. For instance, while over 30 percent of Canadians live in rural areas, only about 14 percent of family physicians and about three percent of specialist physicians practise there. Rural hospital closures and centralization of many health services in larger cities mean that rural residents have more difficulties accessing services. The lack of community services in many smaller centres means that patients discharged early from hospitals often lack community-based care. The list goes on. Not that urbanites do not have difficulties, but residents in rural areas, small towns and remote locations face many more obstacles and those obstacles tend to be much more formidable.

Because the health problems confronting rural Canada are serious, complex, interrelated and evolving, research should have a critical role to play in examining the nature of these problems, monitor their progress or deterioration, identifying their causes, finding solutions and evaluating the effectiveness of various interventions. However, to date, rural health research has not received substantial or sustained support from major health research granting agencies in Canada. Generally speaking, within the health research community, rural health issues are either overlooked or dealt with in a "generic" manner. In "generic" studies, even when rural is mentioned, it is commonly used as a convenient comparison category to illustrate urban-rural differences. Rural is rarely the focus of attention, yet findings and recommendations from urban-based research are often considered universally applicable or are extrapolated to rural settings.

Unfortunately, tried-and-true urban-based approaches may not always work in rural settings. Even on such seemingly uncontentious issues as evidence-based standards of care, there could be differences in perspective. Commenting on evidence-based medicine, Walter Rosser has pointed out that "(t)he geographical context in which health care is delivered in a country such as Canada, with widely scattered small communities far from major medical centres, creates unique problems for the application of medical evidence. Although there may be good evidence that the quality of life of elderly people can be improved by palliative radiotherapy, the practicality of a frail 85-year-old travelling several hundred kilometres to the nearest radiotherapy centre must also be considered.... Thus, the geographical context of the situation affects decisions about treatment, even though good quality evidence may be available to support a specific course of action" (Rosser, 1999: p. 662).

Take another example. In the past, most HIV/AIDS cases were found in metropolitan areas and a multitude of prevention, testing, treatment and care strategies and programs were developed to deal with the crisis. But as HIV/AIDS slowly but steadily spreads to small towns and rural areas, some of those strategies and programs have been found wanting mostly because they are not designed for the rural setting. For instance, many rural physicians who have to look after HIV/AIDS patients find it difficult to keep up with rapid developments in HIV/AIDS diagnosis and treatment because they see very few cases. The social stigma associated with HIV/AIDS and the relative lack of privacy in smaller communities mean that some at-risk individuals do not get tested and some infected persons do not use locally available health services and informal support networks for fear of confidentiality breaches. In some parts of the United States, some rural pharmacies may refuse to carry anti-HIV drugs because there are not enough patients to justify the expenses. As a result, alternative approaches have to be found and different service delivery systems have to be devised, with the unique rural needs and circumstances in mind.

When commonly used health indicators or statistics are examined, the farming population appears to have a health profile quite similar to the general population in terms of morbidity and mortality. However, upon closer examination, farmers are found to have higher rates of certain types of cancer such as cancer of the brain, prostate, skin, stomach and the hematopoietic and lymphatic systems. They are more likely to suffer from animal-borne infectious and parasitic diseases than the non-farm population. They are also more prone to be injured or killed in farm machinery-related accidents. In short, farmers and their families experience special health problems and have special health care needs which tend to be overlooked in general health studies.

These are just a few examples to show the need to view the rural reality through a "rural lens". It is essential that rural health issues be understood in more than anecdotal terms and that rural inhabitants be treated as more than statistical categories. In a similar vein, policies and programs designed to meet rural health needs must be grounded in solid information and sound research analysis. Rural clinicians practise in different and sometimes challenging environments and often have to be innovative and

adaptive in what they do. They may have to do things differently than their urban counterparts. Research can be very helpful in guiding clinical decision-making and in evaluating effectiveness. But such research has to be based in rural reality. Rural health studies must not be seen as an outgrowth of urban-based research and must not be regarded as something that can conveniently be subsumed under other areas of health research.

The important role of research in strengthening rural health has been recognized by a recently released document titled *Toward Development of a National Rural Health Strategy* (National Liberal Rural Caucus, 1999). In it, the National Liberal Rural Caucus laments:

"...that the rural population is a vulnerable one because of occupational risks, for example, of fishing and farming. We also know that seniors, single mothers and their children, and others who lack mobility are vulnerable, too often because of the dual impact of poverty and isolation. A search through publications reveals little research has been undertaken that examine these circumstances and the health care services available to address them in rural Canada" (p. 7).

Because of the numerous knowledge gaps in rural health, one of its recommendations is to strengthen rural health research on such topics as:

"To re-examine occupational risks in rural Canada in order to evaluate the level of health services across the country to ensure access to appropriate health care in a rural context, as well as to identify opportunities to promote preventative measures" (p. 7) and

"To identify the links between quality of life issues and health and to develop mechanisms to address the needs of rural Canadians in ways appropriate to their rural context" (p.7).

Rural health research has helped identify problem areas, find solutions and improve the health status of the rural population. The following are just a few examples:

- Clinical and evaluation studies of telepsychiatry in rural Alberta and Newfoundland have shown that some psychiatric services can effectively be delivered over long distances via telehealth. This could revolutionize psychiatric services in some rural and remote regions where psychiatrists and other mental health workers are few and far between.
- Studies on rural physician shortages have identified a host of factors that affect physicians' practice-

location decisions. As a result, questions have been raised about the appropriateness of rural physician recruitment and retention programs that are based solely on financial incentives or disincentives. In recent years, rural medical workforce strategies have tended to approach the problem from a much broader perspective.

- A community-based research project in Prince George, British Columbia involved First Nations and Métis women in examining the cultural and social context of tobacco use during pregnancy. The nurse researchers then worked with the pregnant women to develop a smoking reduction and cessation counselling model that was compatible with Native values and philosophy. This counselling model has since been adopted in communities across northern British Columbia.
- The Canadian Association of Emergency Physicians has recently published a "Rural Chest Pain Guideline" which has been developed based on research and the experiences of rural physicians and nurses. This exemplifies the need to combine research with clinical practice insights to find workable solutions to health problems in rural settings.

Research on snowmobile-related trauma in northeastern Ontario has resulted in the implementation of safety-education programs for snowmobilers and other accident- prevention strategies. Many lives have been and will be saved as a result.

Scope and Nature of Rural Health Research

Rural health refers to the health of people living in rural, northern and remote areas, as well as small towns. The scope of rural health, from the perspective of research, is very broad. It includes the health status of rural residents and health conditions of rural communities; biological, cultural, ecological, economic, social and other factors that affect the health of rural inhabitants; ways and means to prevent, diagnose, treat and cope with diseases and disabilities; clinical applications in rural settings and biomedical issues that are of concern to rural residents; health beliefs and illness behaviours; lifestyles that adversely affect or maintain health; health care policies and programs that have implications for the rural population; development, supply, use, recruitment and retention of rural health care practitioners; health services delivery, organization and utilization; health care resource allocation; medical/health technologies that support rural health care; formal and informal social support systems in rural communities; etc. For the purpose of this position paper, health is also interpreted in a more holistic sense to include both physical and mental health, as well as social and psychological well-being.

One of the stated objectives of the CIHR is "to forge an integrated health research agenda across disciplines, sectors and regions" (Halliwell and Lomas, 1999). The four major sectors of research are basic biomedical research, applied clinical research, health services and systems research and research

on society, culture and population health. Rural health research, as a microcosm of health research, offers an ideal venue for fostering research integration and collaboration. Rural health research also encompasses the two dimensions of health research. It extends from basic research to applied, mission-oriented research and from research on biology and the individual to research on health care systems and the population.

Multidisciplinary research is a necessity, as well as a reality, in rural health research. By multidisciplinary research, we mean the involvement of investigators from many disciplines who may work independently or in teams. We need biomedical researchers to study the genetic basis of widespread diabetes in some Native reserves, the effects of exposures to agrochemicals on the immune system of farm workers or the health effects of whole-body vibration or heat stress in hardrock mining. Clinical researchers are needed to test the appropriateness of clinical guidelines in rural settings, to conduct randomized controlled trials on drugs developed to deal with diseases commonly found in rural areas or to set guidelines for the safe use of defibrillator by non-medical practitioners in rural emergency departments. Health service researchers can have a major role to play by examining continuity of care as rural patients move to and from urban tertiary-care centres, the effects of alternative payment schemes on rural physician recruitment and retention or the effectiveness of rural outreach chemotherapy programs. As many rural health problems are related to broader social, cultural and economic factors, social and behavioural scientists can make important contributions by examining the cultural basis of rural-urban differences in risk-taking behaviour, the effects on mental health of boom-and-bust cycles in the rural economy or the relationship between informal social support networks and rural residents' self-rated health status.

There are also ample opportunities for interdisciplinary research, by which, we mean researchers from divergent backgrounds collaborating and bringing their varied knowledge bases and perspectives to bear on an issue. Take as an illustration rural telehealth research, a fast emerging area of investigation. Clinicians, health service researchers and social scientists could work together, with the clinicians investigating the clinical application of telehealth in rural practice or defining acceptable standards for telehealth practice; the health services researchers conducting cost-benefit analysis on using telehealth in rural hospitals or examining how telehealth can be integrated into the health care delivery system; and the social and behavioural scientists studying the factors affecting the acceptance or rejection of new technologies by rural residents. Policy analysts could analyze various policy issues arising from the use of telehealth such as reimbursement, licensure, liability and confidentiality protection. Even engineers, other scientists and telehealth providers could be involved in finding ways to overcome the practical challenges of bringing telehealth services to remote communities.

Current State of Rural Health Research

In charting the future course of rural health research in Canada, it is important to know its strengths and weaknesses. As noted earlier, traditionally, rural health has not received the kind of attention and support it deserves. It is not that there is no research on rural health issues. As a matter of fact, there are many studies on a broad range of rural health topics. However, many of these studies are done in a reactive manner, often in response to pressing concerns. Rural health research can also be described as a highly distributed activity. There is a cadre of researchers dedicated to examining rural health issues. But because of the absence of dedicated funding and infrastructure support in the past, there has been a lack of linkages, particularly across research sectors. Researchers, including those working in government agencies, have tended to work in relative isolation, just like the people and communities they study. Not surprisingly, the impact of such highly distributed rural health research activities tends to be reduced and diffused. It has also resulted in considerable duplication of effort and research gaps not being identified. In sum, the major weakness of rural health research is that it is not done in a coordinated, coherent and programmed manner.

Many individuals conduct rural health research without even identifying themselves as rural health researchers. Rural health research is published in diverse journals, books, monographs and government reports. Also, because rural health research (unlike mental health or cardiovascular research) has rarely been used as a competition category by research granting agencies and rarely received substantial, dedicated funding, it is difficult to make a comprehensive inventory of rural health studies or to compile a list of all rural health researchers in Canada. In addition, there is a considerable amount of rural health-related research conducted in-house by officials of various provincial/territorial ministries and health planning agencies. But because most of these studies are internal or unpublished, it is difficult to document the nature and scope of such research activities and the amount of resources devoted to supporting them.

All this notwithstanding, the situation is changing for the better. There is a growing recognition that rural health and the rural quality of life need to be improved. Rural Canada has increasingly emerged as an important focus of attention for policy-makers, particularly at the national level. This is reflected in the active work by many rural advocacy organizations including the Canadian Rural Restructuring Foundation, the formation of the Interdepartmental Working Committee on Rural and Remote Canada, the launching of the Canadian Rural Partnership, the establishment of the Rural Secretariat within the federal government, the recent creation of a new federal cabinet position - the Secretary of State for Rural Development, etc.

Similarly, rural health has received increased attention: special programs in almost every province or territory to address health issues specific to rural or remote areas such as the Underserved Area Program in Ontario and the Rural Physician Action Plan in Alberta; rural medicine programs in many medical schools; a number of rural nursing programs; special committees in some professional organizations to address issues concerning rural health or rural practice; the founding of the Society of Rural Physicians of Canada; the inclusion of a rural health component in the Canadian Health Network;

the recent release of a seminal position paper titled *Toward Development of a National Rural Health Strategy*; and the creation of the Office of Rural Health at Health Canada, one of the responsibilities of which is to identify rural health issues for further research. "As we modernize medicare and continue to help Canadians maintain and improve their health, it is essential that the perspective of rural Canada is reflected in all of our work," stated the Honourable Allan Rock, federal Minister of Health, as he announced the appointment of the first Executive Director of Rural Health (Health Canada, 1998).

There are equally encouraging developments in rural health research. Besides the Centre for Agricultural Medicine at the University of Saskatchewan, the Northern Health Research Unit at the University of Manitoba, the conjoint Centre for Rural and Northern Health Research at Laurentian and Lakehead Universities and the Centre for Rural Health Studies in Newfoundland, several new rural health research centres are in the offing, including the Rural and Remote Health Research Institute at the University of Northern British Columbia. There are other research centres, such as the Atlantic Health Promotion Research Centre at Dalhousie University and the newly established Newfoundland Centre for Applied Health Research at the Memorial University of Newfoundland which, although not identified as rural health research institutes, have a major rural health focus in their research activities. As pointed out earlier, there are many researchers scattered in many universities, research organizations and health care agencies, who conduct some rural health-related studies or whose research has rural relevance. While the numbers of such researchers and studies are sizeable, they are hard to document and the impact of their collective research effort is even harder to gauge.

Other favourable developments include the publication of the *Canadian Journal of Rural Medicine* and several major rural health conferences in recent years. In addition, major initiatives in interdisciplinary and inter-sector rural health research are beginning to emerge. For instance, two major rural health research conferences will be held in the latter part of 1999 at the University of Saskatchewan and the University of Northern British Columbia. The purpose of these upcoming events will be to forge inter-sector and interdisciplinary collaboration and to identify the future directions for rural health research in Canada. Another objective of the University of Northern British Columbia conference will be to launch a Canadian network of rural health researchers. These and other developments suggest that although rural health research has not received its fair share of support in the past, particularly in terms of funding, it is gaining recognition and gathering momentum.

An Institute for Rural Health Research

Compared with some other areas of health research, rural health research is less established as an organized research effort for reasons already noted. But this should not be used as an excuse for not supporting its further development if it is deemed to be a worthwhile endeavour and if research is seen

as a key to improving rural health. Since the CIHR is meant to be a new way of conceptualizing, advancing, organizing and financing health research in Canada, a total reliance on established rules and conventional criteria means that the health research enterprise is no further ahead or is not moving in the intended new direction.

One way to seriously address the health concerns of Canadians residing in rural, northern and remote areas, as well as small towns, is to establish an Institute for Rural Health Research under the CIHR. Although there are different ways to further rural health research, we believe that without an institute to promote, coordinate and fund it, to provide research leadership and direction, to ensure research excellence through a rigorous peer-review process, to further enhance research capacity and to translate research into usable knowledge, progress in rural health research will continue to be slow and sporadic, more by chance than by design. A modest investment, we are convinced, will strengthen rural health research which, in turn, can help to improve rural health. But the investment has to be focused, strategic and programmed.

Alternative Approaches

By necessity, the number of institutes to be established under the CIHR will be limited, but the number of areas of health research that desire or deserve to be recognized as stand-alone institutes is likely to be much larger. This is one of the dilemmas that the CIHR Interim Governing Council will have to face. We need to take this into consideration when deciding how the proposed Institute for Rural Health Research can best be accommodated in the CIHR.

One possibility is not to have a stand-alone institute, but to ensure that rural health research be conducted in a cross-cutting manner. In other words, rural health issues will be "diffused" to different areas of health research. Rural populations will be an "angle" or a "perspective" that needs to be taken into account no matter what kind of health research is done. But this is not that much different than the status quo. This is how rural health has typically been regarded in the health research community. As we have tried to point out, in the main, it has not worked. The rural population has not been well served by such an approach. A cross-cutting approach, in the absence of financial and organizational clout, tends to invite inaction or lip service. Instead of the status quo, rural health research needs a deliberate spur, a defined program, a definitive identity and dedicated funding to help it overcome past benign neglect. This does not rule out doing research in a cross-cutting way, but rural health research requires a different kind of cross-cutting approach.

Rural health research overlaps to a greater or lesser extent with other areas of health research. For instance, it shares many common issues with rural medicine research, but the former is much broader than the latter. Likewise, rural health research intersects occupational health research at many points.

However, rural health research deals with many issues that are not work-related and occupational health research covers many occupations that are not commonly found in rural areas. The same is true with environmental health research, primary care research and so forth.

Rural health research also shares common ground with other areas of research such as aboriginal health research, women's health research, immigrant health research, disability research. The most important common elements are special needs, access and equity. Although the needs may differ from one special population group to another and the problems of access may not be identical, the underlying issues and the research approaches may be similar in nature.

While we strongly advocate the creation of an Institute for Rural Health Research under the CIHR, we are not averse to forming partnerships with those working in related areas. We even see the coming together of some of the related or neighbouring areas of research under one institute as desirable as it may provide a shared focus or afford economies of scale in administration. If a stand-alone Institute for Rural Health Research is unrealistic at this time, we propose, as an alternative arrangement, the embedding of rural health research in a larger entity called the Health of Populations Research Institute.

It is important to differentiate between "population health" and "health of populations". While the former refers to "the conceptual framework for thinking about why some people are healthier than others" (Young, 1998: p. 4) and the entire range of factors that determine health, the latter refers to health issues concerning certain population groups, particularly those with special health needs and/or those requiring special interventions in order to help them overcome their disadvantages. The challenge for the Health of Populations Research Institute will be to ensure as much cooperation and interaction as possible among different groups of researchers under the same roof and, at the same time, maintain their respective identities and research foci. Needless to say, serious alliance- or partnership-building activities will have to wait until there are some clear directions from the CIHR.

Compared to some other areas of health research, rural health research has been conducted in a less organized and integrative manner due to the lack of recognition, dedicated funding and infrastructure support in the past. The proposed creation of the Institute for Rural Health Research or the Health of Populations Research Institute, of which rural health research will be an integral and identifiable part, is meant to redress the balance and to nurture rural health research by providing a supportive, enabling environment. But there is some catching up to do in rural health research as a coordinated and integrative activity.

Thus, we see the first five years as a developmental and consolidation phase, with partnership and research infrastructure building, cementing inter-sector and interdisciplinary collaboration, enhancing research capacity and, most important of all, undertaking a well articulated program of rural health

research on strategically chosen topics as its primary tasks. We also see this as a transformative phase. The Institute, therefore, will not be static. Its mandate, organizational structure, operations and activities are expected to evolve, responding to external and internal changes including developments within the CIHR. At the end of the five-year period, there will be a review of its past performance and its future plans. The next phase of its development will depend on the results of the review and the recommendations of the review panel.

Guiding Principles

If an Institute for Rural Health Research is to be established, it will be guided by a set of principles. These guiding principles, taken together, are intended to safeguard the integrity and quality of rural health research and to shape the development of the Institute. These guiding principles with minor modifications, we believe, are equally applicable to the Health of Populations Research Institute, if it is the preferred option of the CIHR. The principles are:

- *Needs-based Research*: Supports research that addresses the health needs of the rural population, while not ruling out knowledge generation for the sake of knowledge.
- *Policy- and Practice-oriented Research*: Supports research that informs rural health policies and rural clinical practice.
- *An Integrative Research Approach*: Ensures the involvement of and collaboration between different disciplines and research sectors.
- *An Inclusive Research Environment*: Seeks to involve a wider range of people in rural health research, including clinicians and health care planners and managers. Rural health consumers can also become involved in the participatory research process.
- *Research Excellence*: Maintains research excellence through such mechanisms as the peer review system and periodic reviews of the Institute by external review panels. Ensures that the integrative research approach and the participatory research process contribute to quality and excellence.
- *Rural Health Research Methodology*: Where appropriate, adopts a participatory research methodology which emphasizes community input and an understanding of the needs and perspectives of the rural population. Rather than compromising the quality and rigour of research, this can be seen as a "value-added" element in the pursuit of research excellence.
- *Research Capacity Building*: Further develops rural health research capacity by training a new

generation of rural health researchers, providing opportunities for existing researchers to hone their skills and by enlisting or involving clinicians and others interested in rural health in order to expand the cadre of researchers.

Institute-Design Issues

Several institute-design issues in relation to the proposed Institute for Rural Health Research need to be addressed. The purpose is not to spell out the administrative details which are unnecessary and premature at this stage, but to briefly describe how the Institute would function. In discussing institute design, we need to keep in mind the primary objectives of the CIHR and the above-mentioned guiding principles. Although the following points pertain to the Institute for Rural Health Research, we believe they are equally applicable to the Health of Populations Research Institute, if the latter becomes a reality.

· Achieving Integrative and Inclusive Research

Consistent with the objectives of the CIHR, the proposed Institute will be integrative and inclusive in nature. It will encompass research in all four sectors: biomedical research, applied clinical research, health services and systems research and research on society, culture and population health. The types of research to be done will range from basic to applied and from the biological and individual level to the institutional and societal level. This implies that the work of the Institute is not only *cross-discipline*, but also *cross-sector*.

The Institute will put in place mechanisms that encourage and support collaboration among researchers and between research sectors. For instance, funds would be used to support cross-sector research, workshops would be held to promote cross-sector or cross-discipline dialogues, interdisciplinary peer review teams would be used to assess proposals with a view to bringing different expertise and perspectives to bear on a rural health issue, etc. In addition, as rural health researchers are geographically dispersed, the Institute will operate in a *cross-region* manner, mostly with the help of telecommunications technologies. The emphasis will be on networking and "virtual" collaboration by researchers in all parts of the country and, possibly, with those in other countries.

While the mandate of the proposed Institute is to support those dedicated to rural health research, we realize that many studies that are relevant to rural populations or communities may not be done by individuals who identify themselves as rural health researchers and that the Institute may not have the entire range of expertise to address all rural health issues. Thus, it will be necessary to promote rural health research in a *cross-institute* manner. To this end, the Institute for Rural Health Research will set

aside some resources to be used to encourage researchers in other Institutes or even outside the CIHR structure to include rural aspects in their studies.

In some cases, this could be done by providing "top-up" funding to researchers in other institutes who may wish to include rural residents in their samples, to examine specific rural issues in their studies or to conduct part of their research in a rural setting. For instance, an investigator, who belongs to, say, the Institute of Heart Health Research and who is looking at diet, cholesterol and heart disease, can apply to the Institute for Rural Health Research for top-up funding if his/her study sample includes a substantial number of rural residents or if the study addresses some rural-specific issues. The Institute for Rural Health Research may also join force with other institutes to launch special competitions on *cross-issue* research topics such as breast cancer among rural women or the roles of primary care physicians and nurses in providing palliative care to terminal patients in rural communities.

- *Community Involvement in Research*

In order that projects supported by the Institute for Rural Health Research are meaningful, address population and community needs and are policy-relevant, the Institute will encourage and support researchers, where appropriate, to establish partnerships with and/or involve rural residents, rural health care practitioners and those who are responsible for rural health policy formulation.

Because there is greater participation at the grassroots level in decision-making in rural communities, people generally expect to have a voice in initiatives that might affect their lives. This, certainly, would include health research, especially research on health services and systems. The necessity for and the extent of community involvement in health research obviously would vary from case to case. However, such direct involvement - sometimes known as participatory research - is consistent with the ideal of inclusiveness which is one of the objectives of the CIHR and a guiding principle of the Institute for Rural Health Research.

The distinguishing characteristics of participatory research are: (a) extensive collaboration between researchers and the community in each research stage from identifying the research issues to disseminating the findings; (b) a reciprocal educational process between community and researchers and (c) an emphasis on taking action on the issue under study (Green et al., 1995). Having community members take an active role in the formulation and execution of research projects in no way lessens the integrity of the research or the methodological rigour required. Nor does it introduce questionable or untested methods. Rather, it may help to make the research more successful by, for example, increasing the survey response rate or ensuring that the research results and recommendations will be taken seriously.

- *Peer Review Process*

The issue is how to design a peer review system that has scientific rigour and sustains excellence, that promotes innovation and new ideas and that supports new researchers. We understand that the CIHR Interim Governing Council has decided that there will be one system of peer review that will be conducted at the CIHR level, rather than at the level of individual institutes. We believe this decision is sound as it will ensure a uniformly high standard across all institutes and a consistent and possibly more efficient administrative process.

While peer review is widely acknowledged as a key academic quality-control mechanism, it can, depending on how it is conducted and structured, have a constraining effect on innovative and creative thinking in the scientific endeavour. By assessing the quality of applicants and their proposals against the yardstick of established practice within a given discipline, peer review can have the effect of reinforcing orthodoxy or discouraging alternative approaches, particularly for areas of research, such as rural health research, which traditionally have not received a significant amount of attention and support from research granting agencies.

The suggestion here is that peer review can also be used to encourage innovative and creative processes if the peer review committees are appropriately constituted and given a special mandate that reflects a developmental vision. We propose a peer review system which would be modeled after the processes adopted by the Canada Foundation for Innovation (CFI), which uses multidisciplinary peer review committees that reflect the nature of the proposed studies and the constituencies (e.g., industry) to whom they are targeted. Assessment criteria would be specified in such a way as to reflect the goals of the Institute and to direct necessary attention to the rural health mandate. As in the CFI processes, the work of the core committee could be supplemented by external discipline-based reviews to assess scientific and methodological adequacy, where appropriate. The intent is not to dilute the rigour or to lower the standard of excellence, but to supplement the peer review process in such a way that the special characteristics of rural health research (e.g., community participation or involvement of rural health care practitioners in research) could be reflected in the process.

- *Research Capacity Building*

As noted earlier, research capacity building or the expansion of the rural health research critical mass is one of the major and urgent tasks. There are a number of things the proposed Institute for Rural Research can do to enhance research capacity, including:

Rural health research internships to be housed in established rural health research centres should be considered. The purpose would be to expose graduate students in a variety of disciplines to different

kinds or aspects of rural health research, with the hope that some of them would eventually pursue a career in rural health research.

A system of post-doctoral fellowships should be considered, which is designed to attract outstanding new researchers to the area of rural health and help to build a new generation of rural health researchers. These fellowships will be housed in established rural health research centres.

A number of chairs in rural health research should be established at selected universities and/or established centres of rural health research, with a view to developing specialists in this area of research or enabling researchers to spend full-time on rural health research activities.

While rural health research can be conducted in all universities regardless of size or location, experience suggests that most rural health researchers are from regional universities and universities with a special interest in rural economic activities such as agriculture and fishery. Thus, special efforts should be made to support such universities in developing their rural health research capacity.

Funding should target research topics that deal with critical rural health issues that have not received sufficient attention (e.g., addiction prevention and treatment in rural communities, lung cancer among uranium miners, obesity and inactivity among rural residents). This could encourage the development of special expertise needed to address these issues.

Many rural-based health care practitioners are interested in research that is based on their clinical experiences, but may not have the time or the expertise to conduct independent studies. The Institute for Rural Health Research could consider a special "research buddy" program that pairs experienced researchers with practitioners who wish to engage in research. It is hoped that over time, these practitioners will acquire sufficient research skills to become independent researchers.

If an Institute for Rural Health Research is created with dedicated funding and other kinds of support, it will likely attract many researchers from other areas of health research. These individuals, while possessing the requisite research knowhow, may not be well versed in rural health issues. The Institute may consider ways to bring these researchers up to speed by, for example, hosting special workshops or seminar series on rural health issues.

• *Research Dissemination*

Research dissemination will be an important part of the work of the Institute for Rural Health Research. The ultimate goal is to use research findings or lessons learned to improve the health of rural residents by informing clinical and policy decision-making, by developing new health technologies and therapeutics and by designing more effective health service delivery models.

There is little disagreement on the need to disseminate research findings as widely and timely as possible, but there is no consensus on what the most effective approaches are. There are many structural, technological and motivational barriers that hinder effective knowledge transfer and policy uptake. After years of research and trial-and-error experimentation, the flows of information between researchers and clinicians and policy-makers continue to be inadequate. If that is the general case, the situation is perhaps even more problematic with respect to rural health research in Canada, where there are as yet no well-established networks of researchers, where researchers, decision-makers and clinicians are widely scattered and where there are few, if any, well-established conduits between researchers and clinicians and policy-makers. The telecommunications environment for research dissemination has changed dramatically in the last decade, especially with the proliferation of personal computers and Internet access. But the penetration of the latter medium is uneven and it remains particularly difficult in more remote regions of Canada.

Technology transfer and commercialization is an issue that has not been extensively discussed in rural health research, except in selected areas of biomedical research. But the increasing use of telehealth in rural health service delivery and the growing interest in telehealth research have the potential to contribute to the development of Canadian expertise and the growth of new downstream enterprises through technology transfer and commercialization.

These are likely to be some of the challenges facing the Institute for Rural Health Research, as well as the CIHR. The CIHR and its constituent institutes may need to collectively address the issues of research dissemination, policy uptake, technology transfer and commercialization. One possibility would be for the CIHR to establish an office that is tasked to study the issues, find solutions, develop guidelines and offer assistance to institutes, research teams and individual researchers. In addition to all this, the Institute for Rural Health Research would need to examine and find solutions to the problems of research communications which are unique to rural settings and the rural health research community.

- *Budget*

The budget for the proposed Institute for Rural Health Research is based on several assumptions. The first assumption is that financial resources will be allocated equitably across the CIHR institutes. This means that each of the 12 to 15 institutes will get an annual allocation of approximately \$60 million. The second assumption is that some institutes may receive less than the full allocation during an initial developmental phase. The early activities of the proposed Institute for Rural Health Research will include significant capacity building and infrastructure development. An achievable goal of the Institute during the first five years is a doubling of research capacity. A further growth of approximately 50 percent is feasible between the fifth and the tenth year, after which time, the Institute should function at full capacity.

Based on these projected rates of growth in research capacity, the yearly budget of the Institute for Rural Health Research during the first five-year period should increase steadily from \$20 million in the first year to \$40 million in the final year, and then from \$40 million to \$60 million during the second five-year period. In proposing this budget, we have also taken into account the higher costs of conducting rural research, maintaining networks of rural health researchers and disseminating research findings in rural areas due to long distances between communities, high costs of transportation, inadequate telecommunications infrastructure, etc.

If rural health research is to become part of the Health of Populations Research Institute, a similar amount of money would be needed to support rural health research and related activities. However, some economies of scale in administration and infrastructure could be achieved, possibly resulting in some savings.

- *Evaluating Overall Success*

A comprehensive evaluation mechanism should be put in place to measure how well the goals of the Institute for Rural Health Research have been fulfilled. The evaluation mechanism will be shaped by the CIHR objectives and standards, as well as by the guiding principles of the Institute outlined earlier. It is anticipated that within the first year of the Institute's existence, a strategic planning process, which would have been initiated prior to the Institute's inauguration, will be completed. Arising from the process will be the criteria for evaluating:

The Institute's structure such as the number and characteristics of research nodes, the number and types of active researchers, number and nature of research partnerships, communication infrastructure, peer review mechanisms, interaction with researchers affiliated with other institutes, international connections and collaborations, etc.

The Institute's operations which would include the peer review process, the processing of applications and grants, priority-setting mechanisms, allocation of research funds, financial management, the Institute's reporting and administrative relationships with the CIHR and other institutes, dissemination of information concerning the Institute's objectives, activities, competitions, etc.

Outcomes of the Institute's work which would include the demand for funding, number of successful grant applications, number of new grant-holders, number of research-community partnerships, involvement of health care practitioners and policy-makers in research, number of post-doctoral fellowships and graduate research internships awarded, number of publications and conference presentations arising from studies funded by the Institute, dissemination of research findings and publications, maturation of rural health research as reflected in the overall capacity of researchers to

conduct large-scale, networked research, etc.

Effectiveness of rural health research. This refers to the impact of rural health research on clinical practice, policy development, program planning and, most important of all, the health and well-being of rural populations and communities. This is probably the most difficult to assess in an objective and quantifiable manner. Some indirect measures may have to be used such as evidence of policy uptake and knowledge transfer.

Summary and Conclusion

Rural health research in Canada has reached a new threshold. Although devoid of substantial and sustained support from major research granting bodies, it has accomplished much. Conducted by researchers in a variety of disciplines and in research centres, universities and health care agencies across the country, numerous studies have been done which address many important rural health issues. They range from basic to applied research and from the micro to the macro level. However, rural health research activities tend not to be well coordinated, integrative and programmed. Despite its incipient strength and immense potential, for rural health research to make further progress and to have a greater impact on the health of the rural population, it needs support. The creation of the CIHR is most opportune because what the CIHR stands for is exactly what rural health research needs: collaboration among research sectors and researchers, an integrative and inclusive approach in research, emphasis on research excellence and a focus on research for the purpose of improving the health and well-being of Canadians. The CIHR has an opportunity to give rural health research in Canada the needed impetus, identity and wherewithal to ensure its further development.

We believe the best way to advance rural health research in Canada is to create an Institute for Rural Health Research under the CIHR. This would allow rural health research to enjoy the same kinds of financial and infrastructure support that have been accorded other areas of health research. It would also allow rural health researchers from diverse disciplines and research sectors to collaboratively find solutions to some pressing rural health problems. Although the Institute for Rural Health Research is meant to be a stand-alone institute, it is designed to be truly cross-cutting in nature. Research conducted under its auspices will be cross-discipline, cross-sector, cross-region, cross-institute and cross-issue. A modest investment in rural health research, we are confident, will help improve rural health by providing the data and evidence needed to make informed clinical and policy decisions. An annual budget of \$20 million, rising incrementally to \$40 million by the fifth year, has been proposed for the five-year developmental and consolidation phase.

Although it is our belief that an Institute for Rural Health Research under the CIHR is the best option, we realize there may be constraints that would prevent the creation of a stand-alone Institute at this time.

Other viable options exist, one of which is the creation of a larger entity to be named the Health of Populations Research Institute. Rural health research and other areas of research which target populations that have special needs or that require special interventions could come under the Health of Populations Research Institute. Rural health research, however, has to maintain its unique identity within this larger entity in order for it to be viable.

We also realize that rural health research has some catching up to do in order to achieve research integration, to build up the necessary infrastructure and to have a more substantial critical mass of researchers. To this end and adhering to the transformative principle, we propose that the first five years of the Institute for Rural Health Research, or the Health of Populations Research Institute, be considered a developmental and consolidation phase. At the end of the five-year period, an objective review of its performance will be conducted which will, among other things, determine the future course of rural health research and how it will be situated in the CIHR.

The creation of the CIHR has generated a lot of excitement and expectations. Researchers, including rural health researchers, are excited about the expanded opportunities in health research. At the same time, researchers, particularly rural health researchers, expect the CIHR to chart a new course in health research by setting a research agenda that addresses the health needs of *all* Canadians, by supporting areas of health research which need to be strengthened, by being innovative and pro-active in its decision-making and by bringing the health research community together through an integrative and inclusive approach.

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