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CIHR Institute of Population and Public Health Canadian Population Health Initiative

MOVING POPULATION AND PUBLIC HEALTH KNOWLEDGE INTO ACTION



A casebook of
knowledge translation stories



Canadian Institute
for Health Information
Institut canadien
d'information sur la santé



CIHR IRSC

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Canadian Population Health Initiative

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PUBLIC HEALTH KNOWLEDGE
INTO ACTION



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Canadian Institutes of Health Research
160 Elgin Street, 9th Floor
Address Locator 4809A
Ottawa, ON K1A 0W9 Canada

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The views expressed in this report do not necessarily represent the views of the Canadian Institutes of Health Research or the Canadian Institute for Health Information.



CIHR MANDATE

The Canadian Institutes of Health Research (CIHR) is the Government of Canada's agency for health research. CIHR's mission is to create new scientific knowledge and to catalyze its translation into improved health, more effective health services and products, and a strengthened Canadian health care system. Composed of 13 Institutes, CIHR provides leadership and support to close to 10,000 health researchers and trainees across Canada.

IPPH MANDATE

The CIHR Institute of Population and Public Health (IPPH) will support research into the complex interactions (biological, social, cultural, environmental), which determine the health of individuals, communities, and global populations; and the application of that knowledge to improve the health of both populations and individuals, through strategic partnerships with population and public health stakeholders, and innovative research funding programs.

CPHI MANDATE

The Canadian Population Health Initiative (CPHI), a part of the Canadian Institute for Health Information (CIHI), was created in 1999. The mission of CPHI is twofold: to foster a better understanding of factors that affect the health of individuals and communities, and to contribute to the development of policies that reduce inequities and improve the health and well-being of Canadians.

CIHI is an independent, pan-Canadian, not-for-profit organization working to improve the health of Canadians and the health care system by providing quality health information. CIHI's mandate, as established by Canada's health ministers, is to coordinate the development and maintenance of a common approach to health information for Canada. To this end, CIHI is responsible for providing accurate and timely information that is needed to establish sound health policies, manage the Canadian health system effectively and create public awareness of factors affecting good health.



FOREWORD

Knowledge translation (KT) is a broad concept, encompassing all steps between the creation of new knowledge and its application to yield beneficial outcomes for society. Successful KT strategies can include linkage and exchange, communication and education, policy change and program and practice improvement initiatives.

CIHR's vision of successful KT is the exchange, synthesis, and ethically sound application of knowledge within a complex set of interactions among researchers and users—to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products and a strengthened health care system. A core element of CIHR's KT strategy is to support and recognize KT excellence; another is to act as a KT resource for Canada.

KT is also integral to the work of the Canadian Institute for Health Information (CIHI). CIHI's vision is to improve the health of Canadians and strengthen their health system by developing, integrating and disseminating timely and relevant health and health services information and by facilitating informed discussion and evidence-based decision-making.

In early 2005, the CIHR Institute of Population and Public Health (IPPH) and the Canadian Population Health Initiative, a part of CIHI, issued a joint call for KT “stories” that illustrated both successful and less-than-successful examples of the collaborative development and practical use of population and public health research evidence. We wanted to encourage and recognize KT activity and provide a vehicle for publishing and sharing lessons from KT experiences.

We also wanted to highlight the potential impact of population and public health research evidence in shaping changes in policy and practice. There is growing interest among health and other organizations, community groups, individual researchers and decision makers in sharing experiences that lead to a greater understanding of KT in action and its better practices, including, but not limited to, improved programs and policies.

We invited individuals, teams and organizations working in health and other sectors related to the advancement of population and public health to contribute to this Knowledge Translation Casebook.* Cases were selected based on review of the abstracts submitted. The collection represents a naturally broad cross-section of experiences—ranging from the use of research-based theatre in a knowledge translation initiative with injured workers, to developing a community health tool kit in partnership with Indigenous health organizations, to a large-scale international collaboration to identify issues in globalization, gender, and health.

The cases in this Casebook are first-hand, personal stories. We asked contributors to be frank about their successes and failures and to report, from their own experiences, what worked, what didn't and the lessons they learned. This Casebook is not intended to be a replacement for insights gained from systematic reviews of the growing KT literature. But many of these stories echo common themes about conducting KT in the Canadian context.

Lessons learned

- Many cases in this Casebook tell the stories of **KT with communities** that have not traditionally been involved in research or decision making. These partnerships can provide new perspectives on research

* CIHR's Institute of Health Services and Policy Research has concurrently produced a Knowledge Translation Casebook.

challenges, result in better-informed research and create interest in, and improved uptake of, research findings. However, partner roles need to be carefully defined. Formal agreements, which detail expectations and resources to be provided, can be useful, but must be supported by trusting and open relationships. Building this trust can be the biggest challenge in partnerships involving non-traditional or historically wary collaborators. Significant work is often required to establish the requisite understanding of each other's contexts, needs and expectations.

- Importantly, such partnerships can result in a shift to community-based leadership of initiatives to improve programs and practices. But for this to happen and, more broadly, for any KT activity to be optimally successful, there must be **capacity in the community** to adopt new knowledge and adapt to the changes it requires. Capacity building—to enhance efforts to uptake and use research and practice innovations—can make the difference between the success or failure of a KT initiative, and is most effective when supported at an organizational level.
- While the organizational climate is crucial, **individuals can make a huge difference**. A researcher's genuine passion for practice change can play an unquantifiable, yet vital, role in KT, particularly in communities where a demonstrable commitment is a key part of building trust. Such human factors can't always be replicated but it is important to acknowledge their contribution and to capitalize on individual strengths when creating broader KT strategies. It is also worth recognizing that participants in discussion and consensus-building groups need to be chosen with care, as they can be a key determinant of an initiative's success.
- **KT must be tailored to the community**. There are no good KT practices that can be simply and reliably applied to any situation. Good KT is appropriate to its context, and local processes of knowledge uptake and utilization must be understood to create effective KT strategies. Research knowledge risks remaining unused unless it is presented in a way that speaks to its audience, whether through neighbourhood-based maps, youth-oriented websites, or a professional theatre production. However, the old truths about KT—research results need to be timely, clearly presented and contextual—should not be forgotten either. A number of cases here serve as timely reminders.
- **KT is most successful when there are tangible benefits for all partners**. KT is rarely induced by the mere notion that research should be practically applied, and is often ineffective when change is simply mandated without accompanying incentives. KT works best when all partners in the initiative have the possibility of making concrete gains towards their own priorities, shared or otherwise.
- Finally, **KT requires constant effort**. Relationships, particularly with community partners, need to be carefully maintained. This can be a difficult task within the constraints of research funding cycles, particularly in the early stages, when existing funding models and mechanisms rarely support the constant tending that new relationships need. Without such vigilance, however, misunderstandings can arise, commitment can be doubted and research and KT activities can be seriously undermined. The most successful KT initiatives actively evolve in parallel with the needs of their user communities. Success, however, can pose its own problems, when small community-based initiatives are pressed to expand, or when the demand for KT outstrips the capacity of researchers to respond.

We hope that this Casebook becomes a valuable resource for the diversity of population and public health communities in Canada. While we intend that this will be the first of many such efforts to illustrate population and public health research-related KT in Canada, it is a pilot project, and will be evaluated for its usefulness as a source of information about KT in action. We therefore welcome your comments on content, presentation, distribution or any other aspects of this project.



John Frank
Scientific Director
Institute of Population and Public Health
Canadian Institutes of Health Research



Jennifer Zelmer
Vice-President, Research and Analysis
Canadian Institute for Health Information





ABORIGINAL HEALTH

DEVELOPING A COMMUNITY HEALTH TOOL KIT WITH INDIGENOUS HEALTH ORGANIZATIONS

Sylvia Abonyi, Saskatchewan Population Health and Evaluation Research Unit, University of Saskatchewan
Bonnie Jeffery, Saskatchewan Population Health and Evaluation Research Unit, University of Regina

The First Nations Health Development project developed a tool kit, including a community health framework and associated indicators, for use in monitoring Indigenous community health and wellness. Involving nine northern Saskatchewan communities, the Prince Albert Grand Council, the Athabasca Health Authority and researchers from multiple universities, the collaborative project specifically focused on understanding the impacts of physical and social environments on health and building capacity among research and community partners. The project's success was attributed in large part to the trust between partners, and an approach to knowledge translation driven by both community and academic needs and contributions.

Background

The First Nations Health Development project originated with senior health managers at the Prince Albert Grand Council* (PAGC) and the Athabasca Health Authority in northern Saskatchewan. These organizations wanted to better understand how health and other human services contributed to health (or “wellness” in the holistic meaning commonly attached to the term by Indigenous groups) and to determine, from the community viewpoint, the information that should be monitored to assess progress in community health and wellness.

The three-year project created a tool kit that outlines relevant community health domains in a comprehensive framework and suggests indicators to track progress in each domain. The tool kits are designed for use by managers and community-based staff in First Nations and provincial communities to create an evidence base to help guide program and policy decisions.

Our (Abonyi and Jeffery) involvement with the project began with a contract we held with the PAGC to conduct an evaluation of their transferred health services.† The PAGC raised questions around Indigenous health frameworks and indicators beyond the scope and available funding for our mandated evaluation and we began to develop a funding proposal for a collaborative research project. The newly-formed Athabasca Health Authority also expressed an interest in participating and both organizations became collaborators. The project was ultimately funded by CIHR (the Institutes of Population and Public Health and Aboriginal Peoples' Health), the Saskatchewan Health Research Foundation and Northern Medical Services at the University of Saskatchewan.

The KT initiative

Our research initiative and associated knowledge translation (KT) activities specifically focused on understanding and addressing the impacts of physical and social environments on health, and building

* A Grand Council is the elected body that represents the collective interests of its member First Nations governments.

† Health programs transferred from Health Canada to First Nations and Inuit control. Community-based health services under transfer include environmental health and treatment and prevention services, as well as appropriate First Nations and Inuit Health Branch facilities. The decision to enter into transfer rests with each First Nations and Inuit community and, once completed, is required to undergo evaluation at five-year intervals.

capacity: among members of a team of academics and community/organizational stakeholders; and for community/organizational stakeholders to use the research findings.

Our core research activities included a comprehensive literature review to develop a draft community health framework and indicators, followed by interviews and focus groups with health directors and managers from nine northern Saskatchewan communities—each composed of a majority of First Nations and Indigenous people—to develop and refine the draft materials.

Our research team included a large number of individuals with different levels of involvement. The day-to-day core team included the co-principal investigators (Abonyi and Jeffery), a research coordinator and research assistants. Participants with a lesser degree of involvement included collaborators from First Nations and provincial health organizations and health directors from First Nations communities, who were actively involved every one-to-two months in the ongoing development of the framework and indicators. Academic team members, including a multidisciplinary team of colleagues from a bi-university research unit and members of the Indigenous communication arts program at the First Nations University of Canada, were drawn in less frequently to review project materials and assist with dissemination activities.

The KT strategy to link partners working at these different levels together was always implicit and specific KT activities have evolved as the project progressed. We found that these activities must be brief, focused and relevant, and our most successful activities included a visual focus. For example, we used a logic model—a picture showing the linkages between objectives, activities, measures of success in completing activities and the resources required to complete the project—to visually describe the project's research objectives and associated activities.

We presented our results to academic and lay audiences in poster sessions. These posters also proved to be useful progress summaries for our community collaborators and were distributed as 11" x 17" versions. Face-to-face meetings between collaborators were important in the early stages of the project and continued at regular intervals. We are in the process of designing a public website for the project, which will include the tool kit, progress reports, presentations, posters and other deliverables that all team members can access. The final tool kit is also being produced as a hard copy manual and as an interactive CD for direct distribution to participant communities.

Results of the KT experience

These activities resulted in the organization of the final community health framework and associated indicators into a tool kit that can be adapted for use by individual communities. We began the project with the idea of producing a tool kit specific to each of the nine participating communities. However, we found that there was enough overlap in results to create a general tool kit that allows each community to select those indicators most appropriate for its local situation. The framework provides context and justification for the selection and use of indicators of interest.

The tool kit has already been piloted in one community, with an evaluative process to help us identify and address challenges with uptake before the final version is released. Recent opportunities to work with international colleagues also suggest a broader applicability for the tool kit.

Lessons learned

We have identified a number of factors to consider in planning research activities and facilitating KT through this project. These are not necessarily novel (they largely replicate good community practice known by non-researchers for decades), but they are worth some discussion within the framework of researcher/community relationships.

Building trust

Building trust is a central element of the research process and must be planned for. Issues to consider include the geographic location of research activities, researcher visibility, face-to-face interactions of the various partners, and the relevance of the research. Physically locating the research offices close to community collaborators—and outside the major academic setting—has proven to be beneficial. A high level of visibility is particularly important since, historically, Indigenous people gained little from academia, while researchers advanced their careers on what came to be seen as appropriated knowledge. The presence of researchers in the community, and working collaboratively with community leaders, has demonstrated our commitment to providing useful outcomes to local residents.

Physically locating the research offices close to community collaborators—and outside the major academic setting—has proven to be beneficial.

The competitive grant cycle hinders trust-building.

The competitive grant cycle hinders trust-building. During the time that elapses between proposal submission and funding (which for us was one year), community partner turnover may require relationships to be re-established when the project is funded. This is an essential but costly effort that we found we insufficiently accounted for initially in time and resources.

Involvement of community and academic collaborators

We found that the level of involvement of each partner needs to be carefully negotiated and formalized at the outset. We gained community consent through a negotiated “agreement to participate”. This identified what we would return to the communities in the form of deliverables at specific points throughout the project (reports, tool kit, data ownership) and what we would ask from them with respect to their time, human resources and data.

The relationship with our academic collaborators was similarly negotiated. We asked each team member to identify particular aspects of the project they wished to be directly involved in and indicated deliverables for which we would be expecting feedback. However, we have been less successful with our academic colleagues, finding it especially challenging to keep them engaged in the midst of the myriad other projects they are more involved and invested in, particularly in light of shifting project timelines.

Faced with competing demands on our time, priority went to the community side of our KT strategy: the history and context of engaging in research with Indigenous peoples demands this. But we have learned that KT strategies are very different at community and academic levels and both must receive attention.

Collaborator readiness

For academics, readiness includes the recognition that a commitment to community partners may extend beyond the cycle of a single research project and the willingness to share control over the interpretation of results and dissemination activities with community partners.

For academics, readiness includes the willingness to share control over the interpretation of results and dissemination activities with community partners.

The level of community readiness to engage as a full partner in the research project influences both community ownership of the issue and trust building with academic researchers. In this project, the PAGC had 13 years of experience in managing its own health programs and the impetus for the research came from the PAGC itself.

Ongoing development of partnerships

The ongoing development of partnerships and engagement of the communities has been the most important activity in this project. As researchers, we learned that process and capacity activities that take place among partners during the proposal stages must be continued throughout the research process. This is especially significant in light of the differences between academic and community collaborator timelines and expectations.

Conclusions and implications

As a result of this project, we now intend to explore KT activities with community and academic collaborators in proposal development and at all stages of the research process, in a variety of community-based projects—the first of which is an extension of this project. Planning for KT activities, including capacity-building factors and activities at the proposal development stage, may require some innovative approaches to securing funding. Increasingly, however, we are finding that there are funding opportunities for proposal development that require a well-thought out strategy that accounts for the kinds of activities that, in the past, have begun only once a project is funded.



THE MANITOBA FIRST NATIONS CENTRE FOR ABORIGINAL HEALTH RESEARCH: KNOWLEDGE TRANSLATION WITH INDIGENOUS COMMUNITIES

Brenda Elias, PhD, Manitoba First Nations Centre for Aboriginal Health Research, University of Manitoba
John O'Neil, PhD, Department of Community Health Sciences, University of Manitoba

Knowledge translation at the Manitoba First Nations Centre for Aboriginal Health Research emerged through several population health research initiatives conducted in partnership with Canadian Indigenous peoples. An initial collaboration to carry out a regional health survey laid the foundation to share leadership, power and decision making, and resulted in a program to build capacity in the First Nations health planning community through familiarity with the tools and skills of health researchers. Connections between health researchers and First Nations health planners have since led to the incorporation of evidence-based decision making in many First Nations communities.

Background

Knowledge translation (KT) at the Manitoba First Nations Centre for Aboriginal Health Research (MFN-CAHR) involves the exchange, synthesis and ethically sound application of knowledge in a complex set of interactions among health jurisdictions, Indigenous groups, researchers, policy makers, program developers and health care service providers. MFN-CAHR's commitment to KT grew out of several population health research initiatives conducted in full partnership with Canadian Indigenous peoples.

Historically, First Nations health planners and service providers did not have access to trustworthy health information based on the best available research. Most health information was housed within universities and governments, which were inaccessible to First Nations communities. In the mid-1990s, MFN-CAHR and the Assembly of Manitoba Chiefs (AMC) entered into a research partnership with the Assembly of First Nations to implement the provincial component of the national First Nations Regional Longitudinal Health Survey.

A key KT product of this survey was the First Nations Applied Population Health Research Summer Institute, which introduced population health research approaches to First Nations health care directors and providers. Together, these initiatives contributed to new research and KT networks dedicated to reducing health disparities in First Nations communities in Manitoba.

The KT initiative

The partnership struck to carry out the regional health survey laid the foundation to share leadership, power and decision making from design to KT. The survey was successfully launched and achieved a high response rate.

At the dissemination stage of the survey, MFN-CAHR and AMC realized that First Nations health directors and providers would greatly benefit from an opportunity to work directly with the survey data to answer policy-related questions for their tribal areas and communities. Funding was secured from Health Canada's National Health Research and Development Program (NHRDP), and MFN-CAHR and AMC successfully offered the First Nations Applied Population Health Research Summer Institute for one week each summer

over three years to First Nations health planners. The goal of the Institute was to build “receptor” capacity in the First Nations health planning community through familiarity with the tools and skills of health researchers. Additionally, the Institute sought to increase First Nations’ interest in using the survey results by modelling the process of answering complex health policy questions through the data analysis process. For example, participants were asked to develop questions that they thought their communities would like to see answered (e.g. Who is most at risk for diabetes in the community?), and then survey and provincial health data were analyzed in a workshop format to answer such questions.

Today, MFN-CAHR and affiliated researchers and partners are engaged in a wide range of research activities designed to benefit Indigenous communities. Research now extends across the four pillars of CIHR (biomedical, clinical, health systems and services and population and public health), and reflects a strong participatory relationship with Indigenous communities in Manitoba, Canada, North America and internationally. Specific CIHR-funded projects include biomedical and clinical studies of diabetes, osteoporosis, rheumatoid arthritis and asthma; health systems studies of governance in community services; and broad investigations of the social determinants of community well-being, including studies of social capital, cultural continuity and resilience in the Aboriginal workforce. All of these studies involve Indigenous partners from planning and design through to implementation and dissemination.

Research users must exercise a degree of control or ownership over the research process if the results are to be seen as meaningful and useful.

Our KT model is based on the principle that research users must not only participate in the research process from the beginning, but must exercise a degree of control or ownership over the research process if the results are to be seen as meaningful and useful. We engage Indigenous groups, government policy makers, program developers and providers across multiple health jurisdictions, academic disciplines and research areas in a series of workshops and meetings to both guide the research process and ensure that potential users are familiar with the research results and their policy relevance.

Results of the KT experience

These initiatives have fostered new social connections between university-based health researchers and First Nations health planners and led to opportunities to incorporate evidence-based decision making in First Nations communities. Many

First Nations health planners in Manitoba have now made population health research a critical part of their health governance structures and participate in research networks dedicated to addressing health disparities in First Nations communities.

These initiatives also fostered the development of health information systems. The creation of databases derived from both health surveys and provincial health care utilization data has been identified as a priority by First Nations authorities, who recognize the potential for building an evidence base for policy claims on different levels of government. Previously, this initiative was important only to university-based researchers, but the push is now mainly from the First Nations community.

The early success of the MFN-CAHR and AMC partnership has led to the development of new research space at the University of Manitoba, funded by the Canada Foundation for Innovation, and an Aboriginal Capacity and Development Research Environment grant from CIHR’s Institute of Aboriginal Peoples’ Health. Both of

these grants emphasize the need for research to be structured by a university/community partnership, and for KT to be a critical aspect of all research activities. They also focus on capacity building by providing both space and resources to attract Aboriginal peoples into the health research process.

New research space and a dedicated research group have fostered new research networks, many of which have applied to CIHR to undertake studies with KT as a central component. New researchers now have access to the expertise required to establish successful research studies with Indigenous communities.

Lessons learned

Perhaps somewhat ironically, the success of our KT activities has led to a situation where the demands for researcher involvement in the First Nations policy and planning process have outstripped the capacity of researchers at MFN-CAHR to respond. First Nations authorities in Manitoba constantly need to generate information to support their claims on federal and provincial governments for health care resources. Expectations are now that MFN-CAHR resources can be deployed to answer some of these questions in timely ways, but the relationship has been threatened by the reality of equally compelling, university-based demands on the researchers.

Most importantly, much KT activity is still funded at the margins of research grants. MFN-CAHR receives no dedicated funds from any agency to support KT activities. Research grants from CIHR and other funders acknowledge the need for KT, but the time and cost of these activities are rarely funded at the necessary level. Researchers, particularly in a young organization, are also mindful of the realities of advancement in the university, which continue to reward traditional academic progress over community-oriented activities.

The ownership and control of research data is also a contested area. First Nations in Canada have established a set of principles known as OCAP (ownership, control, access and possession of research data) that they expect to govern the relationship between researchers and First Nations communities and authorities. MFN-CAHR was instrumental in developing these principles in the late 1990s in the context of implementing the regional health survey. Similar principles were included in the early research contracts between MFN-CAHR and the AMC, providing a foundation for the development of a trusting relationship.

Reaching agreement around OCAP principles, however, can delay and even curtail research and KT activities. In particular, “possession” of databases generated by provincial or federal data stewards is highly problematic, given confidentiality and privacy legislation. Data generated by researchers must also be protected for the privacy of research participants. Balance is required to avoid exclusionary approaches by either partner, which can foster distrust, lack of participation and conflict. The principles of mutual respect, the privacy and confidentiality of information at the individual and sub-group level and mechanisms for conflict resolution should therefore form an integral part of research agreements. Our experience suggests that, when an organization such as MFN-CAHR is trusted by all partners as an appropriate data steward, then OCAP issues fade somewhat into the background. But when the capacity for ongoing KT activities is limited, this trust can be compromised.

Research grants from CIHR and other funders acknowledge the need for KT, but the time and cost of these activities are rarely funded at the necessary level.

Conclusions and implications

Successful KT, conducted on the margins of research grants, should be celebrated, but it may not be sustainable.

The time and resources required for KT are significant and researchers and partners need to understand both the opportunities and limitations on this kind of activity. Researchers also need to be appropriately supported to make this investment, in terms of both funding and reward systems in the university and with partners. In addition, community partners require resources in order to engage effectively in the KT process. Successful KT, conducted on the margins of research grants, should be celebrated, but it may not be sustainable and may compromise the fundamental character of the partnership if expectations exceed capacity.



UNDERSTANDING KNOWLEDGE TRANSLATION IN AN URBAN INUIT COMMUNITY

Dr. Janet Smylie, Indigenous Peoples' Health Research Centre
Kelly McShane, Institute of Population Health, University of Ottawa
Tungasuvvingat Inuit Family Resource Centre

Through a research partnership between researchers and an urban Ottawa Inuit community, this knowledge translation initiative engaged community stakeholders in planning and implementing a customized prenatal education intervention. By developing a community-specific knowledge translation framework, with a focus on capacity building, the partnership identified the most appropriate sources of health information and means of information dissemination, resulting in an interactive CD-ROM that responded to Inuit learning traditions and local knowledge systems. The success of the initiative has resulted in a continued commitment to an ongoing partnership.

Background

Successful knowledge translation (KT) activities must account for significant cultural differences, including contrasting notions of what knowledge is, between researcher and user communities. Yet there is a paucity of research on Indigenous models of KT in Canada. Indigenous researchers contend that imposed health services and programs are often misunderstood or rejected by Indigenous communities because biomedical knowledge frameworks are incongruent with local understandings of health and illness and local mechanisms for sharing knowledge.^{1,2}

KT for Indigenous communities must, therefore, be premised on contextual cultural understandings. Others have advocated for understanding the user group, the issue, the research, the KT relationship and the dissemination strategies prior to developing knowledge sharing programs.³ We would take this one step further by acknowledging the “user group” as the best source of information about cultural context, and working in partnership with this user group to support its leadership and participation in the KT process.

Our research team focuses on designing and testing models of KT in partnership with Aboriginal communities. Rates of infant mortality and preterm births are disproportionately elevated for Inuit compared to non-Inuit in Canada. Recognizing a problem in access to meaningful antenatal health information in the Ottawa Inuit community, we developed a KT initiative. The partners in this CIHR-funded initiative included the Tungasuvvingat Inuit Family Resource Centre (based in Ottawa), the University of Ottawa's Institute of Population Health, the National Aboriginal Health Organization and the Aboriginal Healing Foundation.

The KT initiative

Initial discussions between the community and researchers suggested that mainstream antenatal education programs were not providing the information that pregnant Inuit mothers and their partners needed and were not being presented through a culturally appropriate medium. Our objectives were, therefore, to identify and describe local systems of health information dissemination and use in the Ottawa Inuit community and to create and test a locally tailored prenatal education tool.

Building on a seven-year relationship as a primary health care provider to many community members, the principal investigator, Dr. Janet Smylie, initiated a research partnership. Over the next two years, a community research agreement was negotiated; focus groups, key informant interviews and reviews of existing prenatal educational tools were conducted; and a community-specific system of health information was developed.

Over the first phase of the project, community members and researchers documented existing knowledge systems and developed a community-specific KT framework. Community members articulated their learning styles and preferences for health information sources and dissemination, and researchers worked in partnership with them to create a KT model that reflected these characteristics.

The second phase of the project involved the development and evaluation of an interactive CD-ROM, which was identified as the best available medium of transmitting health information in the absence of Elders providing face-to-face teaching. The CD-ROM features an Inuit Elder giving prenatal teachings in the Inuktitut language.

We have included a strong evaluation component to assess which features of the KT process were the most important for community members. We have also included an assessment of the impact of the project on health information use and dissemination by key community health information stakeholders and an evaluation of the community-academic research partnership.

Results of the KT experience

The community-specific KT model we developed appears to be quite dissimilar to existing CIHR KT frameworks.^{4,5} In this strongly cohesive community, we found that informal networks of family and community were the most important source of health information and the best means of information dissemination. Also, it was clear that Inuit-specific health information was preferred, especially received from Elders.

Challenges to effective KT included reduced contact with Elders in the urban environment, the shortage of cultural interpreters and the paucity of educational tools in the preferred forms of communication (oral and/or visual). The community reported that most of the Elders lived in the North, with very few based in Ottawa. In response, we developed the interactive CD-ROM, the content of which matched the strong Inuit visual learning and oral traditions. Local knowledge systems were respected by having a community Elder independently prepare and deliver the message.

Our focus on capacity building—for both the researchers and the community—also yielded significant outcomes. Community members were empowered by being present and active throughout the research process, including the development of the community research agreement, data collection, data analysis, CD-ROM development and written and oral dissemination of results. They gained valuable insight and understanding into KT and health research in general. Researchers, for their part, developed their community-based research skills and learned about the local Ottawa Inuit community, Inuit culture, the Inuktitut language and traditional Inuit health knowledge.

In addition, two community members were engaged as research team members, and gained valuable skills in questionnaire development, translating/interpreting, data collection, data analysis and results dissemination. We made it a priority to have these community members participate in presenting research findings at conferences, which not only contributes to community capacity building, but also supports the credibility of the research.

Preliminary analyses of the CD-ROM reveal that it is extremely well received by the community. They particularly appreciate the fact that the message is in Inuktitut and that the tool has been developed by the community. To date, the evaluation of the community-academic partnership has demonstrated successful community engagement in the research process and the development of a respectful research partnership. This partnership carries with it a commitment to sustainability and respect for the community's long-term objectives and goals for its health care services. The continued commitment of all partners to this project, including the preparation of additional funding proposals for both research and health care infrastructure, provide further evidence of the partnership's success.

Lessons learned

Our experience has been an entirely positive one, but not without some challenges. Most notably, building a relationship takes time and ongoing investment from all parties. We found that negotiating the community research agreement was a good way to develop our academic-community research partnership, as it required a clear articulation of expectations, resources to be provided and protocols regarding ownership, control, access, possession and dissemination of information. More than anything else, the most valuable part of this process was the relationship developed between the academic researchers and community members.

We framed the relationship as a process of reciprocal knowledge exchange and, in order for it to be successful, continued patience, mutual respect, diligence and careful communication were required. At some points, the process needed to be slowed down or speeded up in order to match the needs of the community or the researchers, and discussions needed to take place on a regular basis to negotiate the details. Open, frequent and honest communication fostered and maintained a trusting relationship and also encouraged joint problem-solving strategies.

We found that there were tensions between traditional research granting mechanisms and the needs of the community. For instance, we encountered difficulties in arranging for community members to become salaried research assistants, a practice not typical of some granting agencies. Finding solutions that were acceptable to both the community and the university was challenging, and took time, effort and the willingness of both parties to negotiate. Community development approaches to health research will undoubtedly continue to challenge and transform existing academic research policies and protocols.

Another tension arose in integrating our KT research with existing front-line programming at the community site. The research needs and timelines did not always neatly fit into the existing job demands of the community staff. There was pressure on front-line workers to implement the research program, coupled with expectations that existing services would continue to be offered. Efforts had to be made to balance research needs with day-to-day service requirements.

Conclusions and implications

This project is part of a larger CIHR-funded study of KT in Aboriginal community contexts that has documented patterns of health information use and dissemination in three Aboriginal communities in Ontario—the Ottawa Inuit community and two others. Although several themes were common to all three,

Community development approaches to health research will undoubtedly continue to challenge and transform existing academic research policies and protocols.

each community had unique contextual factors that influenced health information dissemination and utilization. Community consultations generated distinct data about health information sources and dissemination strategies, decision-making processes, locally relevant concepts of health, local health services and programs, community structures and mechanisms of interface with non-community systems.

Understanding local processes of knowledge creation, dissemination, and utilization is a necessary prerequisite to effective KT in Indigenous contexts.

These findings confirm that understanding local processes of knowledge creation, dissemination, and utilization is a necessary prerequisite to effective KT in Indigenous contexts. They also challenge current federal health promotion strategies that rely on pan-Aboriginal written health promotion tools, externally channelled to Aboriginal communities via stove-piped federal programs. They also suggest that formative understanding of local community knowledge systems may be important to health promotion more generally, particularly in cross-cultural settings.

The participatory partnership between academic researchers and community members in this KT project engaged key Inuit community health stakeholders in planning and implementing a customized public health intervention in a community-defined priority area. Similar success has been identified in the other two community KT pilot projects noted above, suggesting that these kinds of

partnerships may be an effective method of engaging Aboriginal community members in KT activities more generally.

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CHILD AND YOUTH
HEALTH

KNOWLEDGE TRANSLATION IN THE COMMUNITY: THE EARLY CHILD DEVELOPMENT MAPPING PROJECT

Janet N. Mort, Doctoral Candidate, University of Victoria

The Early Child Development Mapping Project is a population-wide developmental assessment of kindergarten children in B.C. Results of the assessment, which evaluates physical, social, emotional, cognitive and language development, are mapped by neighbourhood and reported back to local communities. Hundreds of community-driven early childhood and family projects have resulted. The project's knowledge translation success is attributed to the researchers' personal commitment to the cause and the resulting community involvement from the earliest stages; the presentation of research findings in a way that supports community uptake; and the development of provincial networks to highlight and communicate successful research use.

Background

British Columbia's kindergarten teachers know that as many as 25% of children arrive on the first day of school challenged in fundamental aspects of cognitive, language, social, physical and emotional development. The experiences in the first six years of childhood have a significant impact on learning, behaviour, health and well-being throughout a person's life.

Since 2000, the Early Child Development (ECD) Mapping Project, under the direction of Dr. Clyde Hertzman of the Human Early Learning Partnership (HELP)* at the University of British Columbia, has been conducting a population-wide developmental assessment of kindergarten children in B.C. using the Early Development Instrument (EDI), a questionnaire completed by kindergarten teachers for each child in their class. The EDI measures a child's development in physical health and well-being, social competence, emotional maturity, language and cognitive development and communication skills.

The EDI results are mapped on a neighbourhood basis to gain a greater understanding of the role of community factors in supporting early child development. These results are then reported back to school districts in public meetings to provide them with information about the school readiness of their preschool population and to help communities assess local ECD programs. Smaller meetings for intersectoral groups are also held in most communities to develop more detailed interpretations.

Partners in the initiative include HELP, the B.C. Ministry of Children and Family Development, the B.C. Minister of State for Early Childhood Development, the six major provincial universities and sixty school districts who are responsible for administering the instrument to kindergarten children. The project has significant support and community involvement in B.C., and has helped policy makers, researchers, service providers, and community members monitor, understand and plan for support for early child development.

As a former school superintendent, my interest in the ECD Mapping Project evolved from my initial scepticism about this unusual union between a health researcher and hundreds of kindergarten teachers. What possible difference could this data make in the lives of young children? My research, the EDI Impact Study, focused on what school districts and their communities did with the EDI data and maps when they were returned to them, to determine if programs or policies changed for the better as a result. In effect, I wanted to assess the impact of what appeared to be a model, community-based knowledge translation (KT) effort.

* For more information about HELP, visit <http://www.earlylearning.ubc.ca>.

The KT initiative

To assess the success of the project's KT activities, I interviewed members of the participating school districts who had supervised the assessments of the children and actively participated in all stages of the mapping project. Forty-one districts agreed to participate in the study over a period of six months. Interviewees included professionals from health, social services, ECD and education.

My study aimed to address four major questions:

1. What processes were used to disseminate the project results in the community and what was the community's initial response to the results?
2. Were the process, data and mapping valued?
3. What issues or problems arose or were perceived?
4. What initiatives or projects have resulted from the experience?

The resulting report¹ was published; presented to all participating school districts, members of B.C.'s Legislative Assembly and all deputy ministers; and posted on the HELP website.

Results of the KT experience

Of all the districts interviewed, only one saw no further need for EDI activity. In contrast, most of the other districts are keen to be involved in continuing efforts to refine the tool and to move forward with other developments, such as linking the EDI data with other measurements. A small number of districts reported that, although there had been initial resistance from some kindergarten teachers to administering the EDI, most felt validated by the process.

There was unanimity on the part of those who attended the community reporting presentations that the personal presence of Dr. Hertzman had a pivotal effect. Dr. Hertzman and HELP staff personally visited all regions and most communities in B.C., initially to persuade teachers, school administrators and community representatives about the importance of the initiative, and then returning to present and explain the project results. Almost all contacts commented on the importance of Dr. Hertzman's contribution and his knowledge, passion and commitment to the EDI project.

Respondents valued the experience for different reasons. For some, the data resulted in intersectoral representatives coming together for the first time to discuss common issues and concerns and to begin planning for action. Some school districts felt that it was the first time they had been presented with hard data indicating why they should become involved in addressing the preschool agenda and used the results to confidently reallocate funding to areas of greatest need in their schools. Kindergarten teachers particularly valued the release time provided by HELP for the assessment task and appreciated the additional information it gave them about their students' developmental issues.

The most frequently raised issue was the complexity of the maps and complications that arose as a result of confusion over overlapping school and community boundaries. A few districts questioned the credibility of the assessment tool and, therefore, the data and resulting interpretation. School districts expressed frustration that, even though the mapping data had raised their awareness of the issues, they were still prevented from taking appropriate action by a lack of funding and by a mandate that restricts their responsibility to the five- to eighteen-year-old population.

The most significant result of the project was the coalescing and strengthening of intersectoral community coalitions that used the mapping data to develop community action plans and services in the geographical areas of greatest need. The result is hundreds of new community-driven early childhood and family projects focused on strengthening social capital and family capacity. They include parenting programs and resource centres; intersectoral centres based on school sites; hearing, sight and dental screening programs; social development programs; nutrition studies; full-day kindergartens; special programs for Aboriginal preschoolers; First Nations reciprocity agreements; relocation of recreational services; preschool community coordinators; literacy intervention programs; family literacy projects; and numerous forms of new early childhood networks.

The result is hundreds of new community-driven early childhood and family projects focused on strengthening social capital and family capacity.

Lessons learned

How do you galvanize an entire province to engage in meaningful change based on data-driven research? How do you bring diverse professionals with different mandates together to share resources for a common goal? How do you inspire grassroots, community-based change?

The ECD Mapping Project has spurred communities in all areas of the province to engage in change on behalf of young children and provides at least three powerful lessons:

1. The researcher's passion for the cause under investigation and the results of the research must be communicated in person, in powerful ways, to those who share the passion for the common cause.

The researchers—Dr. Hertzman and the HELP staff—played a vitally important role in the KT success of this project. The researchers presented compelling arguments for communities to engage in the project and proved the project's worth by returning to present the research data in public meetings, using visually striking, locally oriented maps. This demonstration of personal commitment and communication was identified as a key reason for the project's success.

2. If the results of the research are presented in compelling ways to key community leaders with a commitment and a responsibility to the cause, it is far more likely that the community will assume leadership for the implementation of change.

External support in the form of hard data and maps provided local leaders with the incentive to form and/or strengthen intersectoral coalitions to plan for shared resources and improved services. These leaders were most often self-selected and came from any one of the participating agencies. The intersectoral coalitions have become leading forces in B.C. communities and have implemented hundreds of projects as a direct result of data provided through the ECD Mapping Project.

3. Provincial networks must be created to highlight and communicate successful models that inspire others and help to build momentum.

The formation of provincial networks reinforced community action planning. Pre-existing government agencies shifted their agendas to support the intersectoral coalitions (and, in some cases, were pressured to do so). New provincial networks and new linkages between old networks are emerging to support the coalitions in the form

of presentations at regional conferences, newsletters, university-based gatherings[†] and a new HELP website[‡] designed specifically to support the intersectoral coalitions. Each had its genesis in the ECD Mapping Project.

Conclusions and implications

Many innovative initiatives continue to unfold in B.C.'s communities on behalf of young children. Inspired by ongoing health research, embraced by intersectoral coalitions and galvanized by community resources, these changes mean the future is getting brighter for our youngest learners. While the ECD Mapping Project continues to establish longitudinal data and to sponsor other ECD-related research, the leadership of the implementation phase has shifted from government to a community base. The collaborative development and practical use of population and public health research has resulted in powerful strategies that support all young children—an excellent example of KT in action.

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[†] As a result of the publication of the EDI Impact Study, the University of Victoria sponsored a colloquium, with HELP funding, to bring together parties to discuss the wealth of initiatives being developed in communities across the province.

[‡] For more information, visit <http://ecdportal.help.ubc.ca>.

JOINT POLICY MAKING IN EARLY CHILDHOOD DEVELOPMENT

Nazeem Muhajarine, Saskatchewan Population Health and Evaluation Research Unit, University of Saskatchewan

Thomas McIntosh, Saskatchewan Population Health and Evaluation Research Unit, University of Saskatchewan

Ronald Labonte*, Saskatchewan Population Health and Evaluation Research Unit, University of Saskatchewan
Bryan Klatt, University of Regina

Lan Vu, University of Saskatchewan

Fleur Macqueen Smith, Saskatchewan Population Health and Evaluation Research Unit, University of Saskatchewan

A Saskatchewan research project into the impact families' economic circumstances can have on early childhood development generated a number of complex findings. Rather than speculating on the implications, the researchers convened a roundtable for policy makers and program personnel to jointly discuss policy recommendations. The roundtable session and associated knowledge translation activities sparked significant interest in the research project and resulted in a greater understanding of the research findings. It also set the stage for an ongoing dialogue between policy makers and researchers, and may lead to collaborative research in the future.

Background

We know that children who grow up in unsafe, unstimulating or dysfunctional circumstances—in their families, schools or neighbourhoods—are more likely to have problems, as children and as adults. However, we are less certain how multiple circumstances in a changing childhood environment determine health outcomes. With this Canadian Population Health Initiative-funded research project, we attempted to understand the seemingly intuitive question of how families and neighbourhoods help or hinder children in the earliest years of their lives.

Instead of speculating on the policy and practice implications of our findings, we identified a group of decision makers working in early childhood development, and met with them to discuss policy recommendations.

We examined the impact that families' ongoing economic circumstances have on their children's health outcomes, from birth to age eight, using the population of all singleton children born in Saskatoon and Regina between 1992 and 1995 (a total of 17,544 children). Our investigations focused on the continuing health impact of living in low-income families, but also considered how factors related to families and neighbourhoods contributed to adverse birth and health outcomes.

The Birth Cohort Study generated a large number of complex findings, not easily rendered to simple one-sentence messages. Instead of speculating on the policy and practice implications of our findings, we identified a group of decision makers working in early childhood development, and met with them to discuss policy recommendations.

* Now at the Institute of Population Health, University of Ottawa.

The KT initiative

Our knowledge translation (KT) goals were to give policy makers a more complete picture of early childhood development in the province of Saskatchewan; to begin a process of using the study's results to assess the effectiveness of specific policy interventions (e.g. by highlighting areas or neighbourhoods that might be underserved by specific programs); and to set the stage for ongoing dialogue between policy makers and Saskatchewan researchers in this area.

To formulate a more complete picture of early childhood development in Saskatchewan, we first conducted an environmental scan of the relevant policy landscape in Saskatchewan and Canada.

We then assembled and met with a group of twenty-five decision makers from the provincial government and representatives of community-based organizations in Saskatchewan and Canada. The attendees included policy personnel from the departments of Health, Learning and Community Resources and Employment (formerly Social Services); people responsible for the actual delivery of programs such as KidsFirst (a Saskatchewan early intervention program targeted at high-risk families and areas); individuals involved in community-based research initiatives; and university-based researchers.

We opened our roundtable session with an overview of the results of the Birth Cohort Study, highlighting a few key findings. First, specific neighbourhood characteristics in Saskatoon and Regina appeared to be linked with early childhood health outcomes. Second, some neighbourhoods not currently served by programs such as KidsFirst appeared to be in need of targeted services. Third, cycling on and off of social assistance appeared to have a stronger negative effect on children's use of health care services than did long-term receipt of benefits. Prior to this session, we had distributed a four-page research summary, describing the research questions and key findings. We followed with a presentation of the policy landscape from our environmental scan, and then discussed a series of questions we had posed on the best policy mix for children and how to target services and assess programs.

We subsequently presented the results of both the Birth Cohort Study and the roundtable at the annual general meeting of the Canadian Public Health Association in June 2004. In the fall we produced the report *Understanding the Policy Landscape of Early Childhood Development in Saskatchewan*,¹ which reported both on the environmental scan and on the policy roundtable, and published it in conjunction with a detailed research report² on the Birth Cohort Study. We distributed these reports to our decision-maker group, associate deputy ministers in relevant government ministries and our funding agencies.

Results of the KT experience

Presenting the results of our research at the roundtable session and through associated activities successfully met our KT goals. The policy and program personnel who participated were very interested in pursuing a more detailed and ongoing dialogue with researchers and were eager to explore the analysis presented in both the Birth Cohort Study, and our scan of the policy landscape.

The roundtable session also gave us a better understanding of some of our research findings. While it appeared from our environmental scan that early childhood development policy in Saskatchewan is designed, funded and delivered in a coordinated manner, the actual situation "on the ground" is less coherent, with little coordination between departments and limited ways for community-level program people to participate in the policy process.

This lack of coherence between policy development at senior government levels and program implementation at the community level results in significant gaps or overlaps in service, especially for Aboriginal peoples. It is further complicated by intergovernmental conflict at the federal-provincial level over responsibility and financing of services for Aboriginal peoples, as well as the duplication of services for some targeted populations (e.g. single mothers with young children). In parts of the province, some groups have access to multiple programs delivered by different provincial or local agencies, while other identifiable groups suffer limited access.

Despite these frustrations, there was a clear sense from the participants that many initiatives underway in the province were making important differences in the lives of children. Some programs, particularly KidsFirst and Aboriginal Head Start, were seen as moving in the right direction and deserving of the increased support that had recently been announced in the provincial budget. In particular, participants felt that these kinds of programs were successful not only because of their specific content or mix of services, but because of the way in which communities were actively engaged in their design and implementation.

Our discussions also shed light on findings we thought were counterintuitive: that children's health appears to be worse in families receiving intermittent income assistance (off and on over eight years) than in those families receiving long-term assistance (three or more consecutive years). To the decision makers, such results made sense, as the long-term receipt of social assistance provided a stable, albeit meagre, level of support around which families could develop coping strategies. Moving in and out of the labour market made for increased income instability and higher levels of family stress, in turn leading to poor child health outcomes.

While we had hoped to develop a set of policy recommendations at the roundtable meeting, we realized that this was too ambitious a goal for the initial meeting. Instead, a more realistic goal is to maintain "space" for creative and ongoing dialogue between researchers and policy makers, so that policy recommendations are developed methodically, and at a time to coincide with the policy makers' readiness for uptake.

Lessons learned

When engaging potential users of research findings, we learned that research results, as complex and counterintuitive as they can sometimes be, are understood by a diverse audience and can be the impetus to engage a variety of people at a high level of discussion. For useful dialogue to occur, however, there are a few prerequisites.

First, research results must be clear, timely and well-presented. We developed and circulated our research summary to the roundtable participants well in advance of the meeting. We took great care to highlight the questions that the research was addressing and used a variety of graphs and geo-coded maps to summarize and present our findings. Our audience found maps of the study areas presenting neighbourhood-level results particularly compelling.

The composition of the discussion group is a key determinant of its success.

Second, you need to carefully select participants, as the composition of the discussion group is a key determinant of its success. We strived to assemble a balanced mix of senior level policy analysts, program managers from various provincial departments,

Research results, as complex and counterintuitive as they can sometimes be, are understood by a diverse audience and can be the impetus to engage a variety of people at a high level of discussion.

community-based advocates and university researchers. Many of the participants were familiar with the principal investigator and research team, and also knew each other. This familiarity creates a level of trust and comfort that encourages honest and deep discussion.

Third, you need to animate the dialogue with a few compelling discussion questions. Our questions were informed not only by our research results, but also by our review of early childhood development policy, providing good context for our results and ensuing discussion.

Conclusions and implications

This experience has confirmed to us the utility of stronger researcher-policy maker interactions. The nature of the study made it of particularly high interest to the policy makers and program personnel, many of whom requested to be both made aware of future work in this area, and to participate in future studies.

But a great deal of work remains to be done in terms of how we build and sustain linkages between researchers and policy makers. Sometimes the researcher-policy maker linkages need to be built on a case-by-case basis, as we did in this project. Other times, these linkages need to be channelled through existing advisory committees for policy making, such as Saskatchewan's intergovernmental committee on Human Services Integration Forum. In any event, we need to focus on making linkages earlier in the research process (so they can influence the nature of the research questions) and on using them to validate research findings in a manner that leads to both deepening existing analysis and pointing to directions for further research.

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THE CANADIAN ADOLESCENTS AT RISK RESEARCH NETWORK: RESEARCH FOR AND WITH YOUTH

Diane Davies, MSc, Social Program Evaluation Group, Queen's University

Will Boyce, PhD, Social Program Evaluation Group, Queen's University

The Canadian Adolescents at Risk Research Network (CAARRN) is an interdisciplinary research program focused on adolescent health. CAARRN's comprehensive knowledge translation strategy targets multiple audiences in both the health and education sectors, including researchers, policy makers, program developers, clinicians, community agencies, school boards, educators and young people themselves. CAARRN also incorporates a youth engagement component that enables research by and for youth. CAARRN's extensive knowledge translation activities have resulted in the uptake of research findings by a number of diverse organizations and the development of a national network of youth researchers and associated personnel.

Background

Adolescence is a time of transition, involving physical, psychological, social and vocational changes. But very little attention has been paid to developing health policy based on current Canadian data for this important population group. In particular, research that illustrates the influence of school and neighbourhood settings, family and peer groups, coping skills and socio-demographic factors on health behaviours and outcomes has been underutilized in policy formulation.

The Canadian Adolescents at Risk Research Network (CAARRN)* is an interdisciplinary research program focused on adolescent health. It facilitates knowledge exchange, communication and collaboration among youth, researchers, policy makers and programmers to improve the quality of life of young people. Through studies of national and international data in seven key areas—bullying, sexual health, injuries, school culture, disability and chronic conditions, social capital and obesity and physical activity—CAARRN aims to better understand the complex interrelationships that have an impact on the health status and daily lives of adolescents, and to facilitate policy development in these areas. The knowledge developed through CAARRN, apart from its value as basic research, is enhancing our understanding of appropriate foci and timing for preventive interventions and the extent to which interventions must be specifically tailored to adolescent sub-populations.¹

CAARRN involves researchers, policy experts and young people from Queen's University, the University of Toronto, Bloorview MacMillan Children's Centre, the Public Health Agency of Canada, the Canadian Education Association and the Centre of Excellence for Youth Engagement. The program is funded (2001-2006) by the Canadian Population Health Initiative (CPHI).

The KT initiative

CAARRN, in conjunction with CPHI, has developed a comprehensive knowledge translation (KT) strategy. The broad relevance of the adolescent health topics addressed in the CAARRN program means that many audiences in both the health and education sectors are targeted, including researchers, policy makers, program developers, clinicians, public health agencies, community agencies, government agencies, non-government

* For more information about CAARRN, visit www.educ.queensu.ca/~caarrn/.

organizations, school boards, educators and young people themselves. We view any meeting as a KT opportunity, and take dissemination products (usually fact sheets) to distribute among participants. We also engage our stakeholders to help us develop and disseminate our KT products.

Our targeted KT activities include:

- *Peer-reviewed publications and academic conferences:* We present our research findings in the traditional forums of academic journals and presentations at provincial, national and international academic conferences.
- *Other publications:* We produce research reports, an electronic bi-annual newsletter, research fact sheets and plain-language articles in local, provincial and national agency publications.
- *Media relations:* We have developed relationships with Queen's University and Canadian Institute for Health Information media representatives to facilitate press coverage of our research findings. For example, two recent publications—comparing overweight and obesity prevalence in school-aged youth from thirty-four countries, and the associations between being overweight or obese with bullying behaviours in school-aged children—received a great deal of media interest.
- *Website:* We develop and maintain a website containing program information, results and downloadable dissemination products.
- *Listserv:* We use a listserv to distribute findings, dissemination products and announcements pertaining to adolescent health research and policy to our array of stakeholders.
- *Rapid response policy team:* We have a rapid response team that responds quickly to issues that arise in the media or in the policy domain. For example, we provided advice to Health Canada on the *Canadian Youth, Sexual Health and HIV/AIDS Study*, and advice to local school boards on policy development regarding bullying.
- *Network meetings:* CAARRN network meetings establish research objectives and provide opportunities for collaboration, data sharing and identification of research gaps.
- *Regional policy workshops:* We host regional workshops to share our research findings with policy makers and researchers around the country and to develop the national network of youth health researchers.
- *National policy conference:* We host a national policy conference targeting local, provincial and federal decision makers in adolescent health, as well as youth organizations/advocates and researchers.
- *Student educational activities:* We have developed student activities for use in school settings based on adolescent health risk behaviour data and findings.
- *Regional outreach/local engagement:* We present our research findings to local schools and school boards, and develop targeted dissemination items upon request.

CAARRN also has a youth engagement component, which is separately funded by the Public Health Agency of Canada's Population Health Fund. It aims not only to facilitate research by youth and through youth organizations, but also to learn from youth and to model methods of working with youth. The Youth Engagement in Health Research and Policy project provides an opportunity for in-depth interaction with young people that involves skill development, basic research training and mutual learning in self-directed health research projects on topics of importance to youth themselves.

Each KT activity has an evaluation component. Meetings and workshops are evaluated with questionnaires and telephone interviews have been conducted with youth researchers to gather feedback on their experiences. Listserv member counts and the dissemination of CAARRN products are also monitored.

Results of the KT experience

CAARRN research findings have been used by a number of organizations, including the Canadian Mental Health Association for bullying prevention program development.

CAARRN research findings have been used by a number of organizations, including the Canadian Mental Health Association for bullying prevention program development, local school boards for bullying prevention policy development and the National Children's Alliance for a position paper on the need for a youth policy agenda in Canada. As well, Statistics Canada is using CAARRN data in its E-STAT program, an interactive teaching and learning tool for the education community, and the Public Health Agency of Canada's Division of Childhood and Adolescence utilizes CAARRN findings to inform program and policy development, as well as to monitor adolescent health behaviours.

Several of the Youth Engagement in Health Research and Policy projects, all of which are now complete, produced meaningful research that has been disseminated and utilized across the country. Research on street youth engagement and stereotypes has been well received by both peers and researchers, and has been requested by those working on the front lines with street youth in communities across Canada.

A national network, including existing regional networks in the Atlantic provinces, Ontario and British Columbia, has now been established, and data sharing agreements have been developed with academics and community organizations. In addition, stakeholders are now contacting CAARRN with their information needs, including requests for data files and tables. This is, in part, attributable to the long-term presence of CAARRN, which has established relationships and developed rapport with various communities and sectors.

Lessons learned

Although our KT activities are still underway, several key lessons can be shared from our experiences to date.

KT products need to be developed with audience representatives to be most useful. Concise, reader-friendly materials work best. By far the most popular CAARRN products are research fact sheets. These targeted, one-page summaries of research findings on a particular topic appeal to all audiences—researchers, policy makers, program developers and young people. We have created a template from which researchers can quickly draft fact sheets (which are similar to structured abstracts, but more user-friendly and policy-relevant) from a finished journal article.

Promoting equal partnerships with adolescent health stakeholders has been an important aspect of CAARRN. The most effective and comprehensive KT events have been our regional policy workshops, which bring together researchers, local policy makers and program developers to discuss the implications of our research findings. We have often collaborated with other organizations and researchers to ensure a more successful and high profile event. For example, CAARRN has teamed up with researchers at Dalhousie University, the University of Waterloo and the McCreary Youth Foundation to host regional policy workshops across the country. Our evaluations indicate that participants find short presentations (fifteen minutes) and opportunities for group discussions to be the most useful aspects.

Engaging young people in their own research—from design, implementation and analysis, to KT, advocacy and participation in policy development—is a challenging and rewarding experience. A key indicator of success is the capacity building within young people themselves, with the lessons learned flowing into other aspects of their lives—school and work particularly.

We also learnt a lot about the evolutionary nature of youth participatory research, as opposed to traditional linear academic approaches. Research with youth offers many lessons and challenges, most of which derive from the complex nature of youth lives. The success of participatory action research has to be judged on more than the traditional markers of academic achievement. Youth empowerment is one of these new indicators:

“I like the process itself, you know, giving young people the skills they needed to do research on the issues we wanted. Having the opportunity to create your own project and do the research on something that you are interested in, and having the support for doing that, is awesome.”

Conclusions and implications

While funding for CAARRN ceases in March 2006, it is hoped the network will continue, with established relationships and new collaboration between youth, researchers, policy makers and programmers aiming to improve the quality of life of young people. CAARRN will continue to support the initiative to develop a national youth policy agenda as a member of the National Children’s Alliance.

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SHOULD WE TEACH HARM MINIMIZATION TO TEENAGERS IN SCHOOL? THE PRODUCTION AND TRANSLATION OF CONTROVERSIAL NEW KNOWLEDGE IN ADDICTIONS

Christiane Poulin, MSc, FRCPC, Canada Research Chair in Population Health and Addictions, Dalhousie University

Jocelyn Nicholson, BEd, BScH, SCIDUA coordinator, Dalhousie University

Researchers from Dalhousie University partnered with the provincial Department of Health, regional Addictions Services, school boards and schools in Nova Scotia in a cooperative participatory research project (SCIDUA) to determine if harm minimization should be adopted as the basis of drug education for junior and senior high school students. Knowledge translation was an integral aspect of SCIDUA and appeared to result in policy change in two partner institutions. However, the success of the knowledge translation may have contributed to the early adoption of harm minimization policies, which failed to reflect some important but unexpected results of the completed research.

Background

While harm minimization is increasingly being advocated as the basis of school-based drug education, there has been little empirical evidence as to its acceptability and effectiveness. We conducted an *Integrated School- and Community-Based Demonstration Intervention Addressing Drug Use Among Adolescents* (SCIDUA) to determine if harm minimization should be adopted as the basis of drug education for junior and senior high school students in Nova Scotia.¹ SCIDUA was a partnership project funded by CIHR, the Nova Scotia Department of Health, Addictions Services in District Health Authorities 1, 2, 3 and 9, the Halifax Regional School Board, the Annapolis Valley Regional School Board, four schools and Dalhousie University. The main goal of SCIDUA was to decrease harmful involvement with, and harmful consequences of, alcohol, tobacco and other drugs. The SCIDUA fieldwork took place from 1998 to 2002.

The KT initiative

The need to allow and encourage open dialogue among students, teachers, administrators and parents about this controversial and untested new policy in drug education led us to use cooperative participatory research.² In cooperative inquiry, people participating in the research are acknowledged as self-determining, and what they do and experience as part of the research must be determined by them to some significant degree.

School Community Steering Committees (SCSCs), comprising students, teachers, the school counsellor, an Addiction Services staff member and a SCIDUA project coordinator, met every two weeks during the school year. Several SCSCs also included parents, law enforcement professionals, local government and community groups. The SCSCs were responsible for creating and implementing drug education initiatives as they deemed fit in their respective schools. Interventions included activities such as public service announcements, student presentations, parent information sessions and teaching videos. A memorandum of understanding and advisory committees allowed for collaboration among the partner institutions, with the advisory committees meeting monthly during the school year. Thus, the overarching process by which the four schools arrived at their interventions was the same, but the actual interventions and mix of interventions were unique to each school.

Our formal evaluation of the acceptability of harm minimization drug education was based on an analysis of 491 documents generated by about 150 informants engaged in the SCSCs or arising from their activities, from 1998 to 2002. Our formal evaluation of effectiveness was based on a survey of 1,117 and 849 students in the intervention schools, compared with 3,755 and 4,247 students in the rest of the province, in 1998 and 2002 respectively.

These evaluations revealed different results among senior and junior high school students. In senior high school, there was decreased prevalence in specific risks and negative consequences of alcohol and cannabis use, and qualitative evidence that harm minimization was acceptable. In junior high school, however, SCIDUA revealed that harm minimization was not acceptable and had not been implemented to any extent, and that there was a failure to demonstrate improvement in the prevalence of specific risks and harms of substance use. We concluded that school-based harm minimization may be acceptable and effective in senior high schools, but may not be acceptable or effective in junior high schools.

Results of the KT experience

Due to its cooperative participatory research design, knowledge translation (KT) was an integral aspect of SCIDUA from its inception. KT activities were extensive and occurred both during and after the fieldwork. Representatives of the institutional partners actively participated and received ongoing documentation through minutes, presentations, updates, summaries of activities, formal reports and local workshops. Based on the high level of engagement of many stakeholders at many levels throughout four years of fieldwork, resulting in a total of 3,000 files of qualitative data, it is clear that the participatory research process of SCIDUA was successful.

However, how do we know that the KT activities of SCIDUA, which were an integral part of the participatory research, actually resulted in policy development in health or education?

Two policy documents developed by partner institutions during their participation in SCIDUA suggest that our KT activities were successful in influencing policy. The first document, which pertains to student substance use policy, was published in November 2002 by the Nova Scotia Department of Health and indicates that their “advocated approach” to drug education and policy is harm minimization, and that the “traditional approach” of zero tolerance is “not a good idea”.³ To our knowledge, this is the first document from the provincial Addictions Services that explicitly identifies harm minimization as the preferred option for drug education. The provincial Addictions Services was an early partner in SCIDUA for the express purpose of answering this policy question, and references in the document point to individuals and agencies involved in SCIDUA.

The second document is a school board substance use policy which adopts the language of harm minimization.⁴ The policy was created during the last two years of fieldwork by one of the school boards involved in SCIDUA, through a committee whose membership comprised, among others, several members of a SCIDUA advisory committee.

While these policies may be viewed at least in part as products of successful KT activities, they were developed before definitive conclusions could be drawn from SCIDUA as a research project. In fact, they were articulated before the sharing of preliminary findings in October 2002 about the doubtful effectiveness of harm minimization drug education targeting younger adolescents.

Lessons learned

So why did two partner institutions involved in SCIDUA seemingly adopt harm minimization in the absence of actual evidence about its effectiveness as a basis for drug education? Here, we distinguish between support for the participatory process of SCIDUA versus support for the policy being researched through the participatory process. Based on our comprehensive analysis of the qualitative data collected during SCIDUA, it appears that the success of SCIDUA as a participatory project may have been misconstrued by some participants as acceptability of the policy direction itself; that is, as acceptability of harm minimization drug education.

A second reason that harm minimization may have been endorsed early is that the rich ongoing reporting and evaluation activities of SCIDUA could have been interpreted by some partners to be conclusive evidence supporting harm minimization. For example, midway through the fieldwork, an interim process evaluation conducted by an external team indicated that progress was being made towards the main goal of SCIDUA. The external team concluded that “a number of adolescents report less frequent and/or less risky use of substances. ... Some stakeholders are committed to the concept and implementation of a harm minimization approach.” Such statements may have been viewed by some SCIDUA partners as proof that harm minimization drug education was acceptable and effective. In reality, the external team’s conclusions were based only on a site visit and on the opinions of a small number of people at one point in time, without the benefit of the pre/post outcomes evaluation, which was a key feature of the formal evaluation. Similarly, two workshops conducted just before the end of the fieldwork appear to have left some participants with the impression that harm minimization was conclusively known to be the correct approach to school-based drug education. In fact, the presenters at those workshops emphasized that the outcomes evaluation had yet to be done and that preliminary information was being shared at that time because the school year and fieldwork were coming to a close.

A final reason that harm minimization may have been endorsed early is that empirical evidence is not in fact a prerequisite for policy making. In the case of SCIDUA, our conclusion that one size does not fit all for junior and senior students was new and unexpected: the international literature supporting harm minimization drug education has tended to not distinguish between older and younger adolescents. Clearly, this particular finding of SCIDUA presents a challenge from the perspective of institutions and individuals in either health or education who wish to opt for a single drug education and policy appropriate for all students, spanning primary to grade twelve.

Conclusions and implications

Early or ongoing KT can pre-empt two essential steps of quality control in science.

We have come to understand that a novel approach like harm minimization can be very seductive to health and education policy makers, particularly if it seems to be a panacea to as difficult a problem as adolescent substance use. Thus, an important lesson learned from SCIDUA is that the participatory process, while helpful in creating a groundswell of commitment to a research process and actively engaging stakeholders in ongoing KT, also risks the premature adoption of inconclusive research findings, some of which may ultimately prove to be wrong-headed. In effect, early or ongoing KT can pre-empt two essential steps of quality control in science: the use of comprehensive rather than selective information and the performance of a

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KT must incorporate mechanisms for the users of research to be invited to re-visit findings and issues.

dispassionate peer review of the research findings. KT must, therefore, incorporate mechanisms for the users of research to be invited to re-visit findings and issues. In the case of SCIDUA, KT activities have been planned past the end of the analysis phase, with the dissemination of the final results targeting SCIDUA partners as well as a broader audience.

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WOMEN'S HEALTH

THE HEALTHY BALANCE RESEARCH PROGRAM: KNOWLEDGE TRANSLATION FOR WOMEN'S UNPAID CAREGIVING

Carol Amaratunga, Ontario Women's Health Council Chair, University of Ottawa

Brigitte Neumann, Nova Scotia Advisory Council on the Status of Women

Barbara Clow, Atlantic Centre of Excellence for Women's Health, Dalhousie University

Viewing knowledge generation and translation as a continuous process, the Healthy Balance Research Program (HBRP) brings together researchers, policy makers, health practitioners and the wider community to develop a comprehensive picture of the unpaid and generally invisible work of family caregivers in Nova Scotia. The HBRP has developed extensive community linkages through equity reference groups representing marginalized women's groups. These groups provide social insight into the research process and social oversight of knowledge translation and policy uptake activities. The success of the program's knowledge translation activities has resulted in significant national uptake of HBRP research findings.

Background

Women have always been guardians of public health and caregivers to family members who are not able to look after themselves. Health policy makers and health care professionals acknowledge that caregiving work is usually performed by women. However, the scope of that work, its economic and health consequences and the policy and program interventions that would offer support to those in the caregiving role are not well defined or understood. This is particularly the case for women who are marginalized by race, ethnicity, Aboriginal status or disability. With increasing policy concern about declining birth rates on the one hand, and an older population with higher dependency on the other, there is increasing recognition that support to women and families needs to become more effective.

The Healthy Balance Research Program (HBRP)* aims to develop a comprehensive picture of the unpaid and generally invisible work of family caregivers in Nova Scotia. It brings together more than twenty-five researchers, policy makers, health practitioners, communications professionals and members of the broader community to provide useful information to caregivers and their communities and to the health care and public policy domains. The program has a particular commitment to the inclusion and participation of women whose concerns are often not considered.

The HBRP is funded and administered as a CIHR Community Alliance for Health Research initiative through the Atlantic Centre of Excellence for Women's Health at Dalhousie University, but is physically located at the offices of the Nova Scotia Advisory Council on the Status of Women, a provincial government agency. The Advisory Council has a legislated mandate to advise governments and bring forward the concerns of women; core functions of policy and research, information dissemination and community education and community liaison and rural outreach; and strategic goals of social inclusion, economic equality and improving women's health. The Women's Health Research Unit at the University of Ottawa's Institute of Population Health is the third partner.

* For further information about the Healthy Balance Research Program, including publications, see <http://www.healthyb.dal.ca>.

The KT initiative

The HBRP conceives of knowledge generation and translation as a continuous process. Much social science research, particularly when grounded in principles of action research, emphasizes the need to include subjects in the research process itself—from setting the research question, to determining appropriate, effective and ethical implementation and, finally, in utilizing the results at political, policy and community levels.

The HBRP began as a partnership between an academic principal investigator (Carol Amaratunga) at the Atlantic Centre of Excellence for Women's Health and a community principal investigator (Brigitte Neumann) at the Nova Scotia Advisory Council on the Status of Women. When Carol Amaratunga later moved to the University of Ottawa, the research partnership evolved into a triumvirate with three co-directors (Barbara Clow, as director of the Atlantic Centre, joined the project as the third principal investigator).

The co-directors share responsibility for overall project policy and co-management. We bring together individuals and organizations interested in caregiving as a research topic and a policy and program issue, and see the project as an interactive “web” of people with shared ownership. The HBRP has teams dedicated to qualitative research, quantitative research, secondary data analysis and ethnographic “household” portraits.

Reference group members are useful critics, pointing out the weaknesses in secondary data that do not reflect the realities of caregivers of various cultural backgrounds and ability status.

In order to address the issues of compounded inequality and marginalization, we also have four equity reference groups: women of African descent, women with disabilities, Aboriginal women and immigrant women. Research team members meet with the equity reference groups to present findings and to incorporate their feedback into ongoing research. Reference group members help to structure research questions, recruit participants for qualitative research and interpret research findings. They are useful critics, pointing out the weaknesses in secondary data that do not reflect the realities of caregivers of various cultural backgrounds and ability status. Furthermore, they are key players in developing ways to feed research findings back to their communities, who are then able to bring both concerns and potential solutions to the media, policy and program officials and elected representatives.

We communicate our research findings back to stakeholder communities in three ways. First, we hold press conferences and publication releases to present our research findings and policy recommendations to the media. Second, we host forums with decision makers and policy audiences to review our research findings and discuss implications for policy change and action. They in turn share HBRP reports, fact sheets, and research findings with members of their respective community constituencies and networks. Third, we hold semi-annual and annual retreats, think tanks, and meetings with our four equity reference group leaders. Through its appointed members and staff, the Advisory Council also brings research findings to groups such as the African United Baptist Association Women's Institute, the Nova Scotia Native Women's Association, the Nova Scotia League for Equal Opportunities, and the Human Resources Association of Nova Scotia.

Results of the KT experience

To date, the HBRP research findings demonstrate that the currently available patchwork of benefits needs to be fundamentally revised to provide all Canadians, both women and men, with fair support for their caregiving roles. Issues such as exhaustion, isolation and difficulty in dealing with care bureaucracies face caregivers in both urban and rural settings. The expectations facing women in our equity reference groups are, if anything,

even higher than those faced by mainstream women. We need to translate increased recognition for caregivers, better support for caregivers, and a deepened grasp of the relational and reciprocal aspects of caregiving into practical and effective measures for implementation at the health practitioner and organizational level, the employment practices level and the level of tax and transfer policies.

HBRP funding concludes in March 2006. As our four qualitative and quantitative research projects near completion, we will build on preliminary work to develop policy briefings for provincial and federal officials. For example, work related to tax and transfer policy affecting caregivers was presented to the 2004 annual forum of the Ministers Responsible for the Status of Women. As well, we co-hosted a national workshop where researchers and decision makers met to consider various models of financial compensation for caregivers. That workshop will in turn serve as a springboard for a national roundtable between the HBRP and the Canadian Policy Research Networks (CPRN) to explore Canada's health and social policy architecture in relation to unpaid caregiving. This event will bring together researchers and policy makers from government, community, clinical and academic sectors, and will synthesize data and findings from both the HBRP and another federally funded project on the marginalization of dependent adults.

Lessons learned

Media coverage of research results raises awareness in the general public, but is also helpful in attracting the attention of other target groups, including professional associations, community groups, affected individuals and the politically active. We had an extremely positive experience in communicating research results documenting that women's paid and unpaid work levels are high and, in certain caregiving situations, stressful, with good local attendance and national-level uptake. However, while positive media coverage is highly desirable for placing an issue on the public agenda, additional approaches are essential.

Media coverage of research results raises awareness in the general public, but is also helpful in attracting the attention of other target groups.

The equity reference groups are perhaps the most important KT mechanism of the HBRP. They have provided invaluable advice and counsel throughout the life of the project, from the early conceptualization of qualitative focus groups, through the design of a

Reference group members have been instrumental in helping the research team members establish linkages with their communities.

quantitative survey and ethnographic household portraits, to the national CPRN policy forum. Reference group members have been instrumental in helping the research team members establish linkages with their communities, particularly in recruiting individuals and households to participate in the research and community meetings. They have also served as an important "accountability" sounding board for the research team members and have helped to ensure that the research remains culturally sensitive.

Conclusions and implications

The knowledge translation (KT) skills required to bring research findings about the lived realities of caregivers to communities, professionals and policy audiences are varied. Good media support, the ability to work cross-culturally and cross-sectorally, the ability to link community groups and policy makers, strong networking and coordination skills and a willingness to move beyond the beaten path are essential.

It is important to keep in mind that this kind of KT may not be rewarded within academic settings: the young scholar would definitely be advised to prepare papers for publications in high-impact journals, rather than spending scarce time discussing the implications of research findings with a group of rural women. But the benefit of working in a partnership is that what is on the periphery of one organization's mandate is at the centre of another's, meaning that time and resources can be committed to valuable KT activities.



THE WOMEN'S HEALTH SURVEILLANCE REPORT: TRANSLATING RESEARCH TO POLICY

Marie DesMeules, Public Health Agency of Canada
Claudia Lagacé, Public Health Agency of Canada
Donna Stewart, University of Toronto and University Health Network
Arminée Kazanjian, University of British Columbia
Heather Maclean, Centre for Research in Women's Health
Bilkis Vissandjée, Université de Montréal

The Women's Health Surveillance Report (WHSR) was a multi-sectoral initiative aimed at making a significant contribution to the understanding of gender-related health disparities in important areas of women's health. The WHSR represented a significant knowledge translation effort, involving an interdisciplinary systematic review of existing research, the development of recommendations for improving health surveillance activities and setting policy for women's health priorities and the use of a variety of dissemination strategies to reach diverse audiences. Significant uptake of the report's findings and recommendations, by practitioners, policy makers, researchers and the general public, was achieved.

Background

In 1999, the final report of the Advisory Committee on Women's Health Surveillance highlighted the need for enhanced analysis of gender as a determinant of health in national health surveillance.¹ This provided the starting point for the *Women's Health Surveillance Report: A Multi-dimensional Look at the Health of Canadian Women* (WHSR), which aimed to make a significant contribution to the understanding of gender-related health disparities with respect to determinants of health, physical and psychological health status and the use of health services.

The purpose of the WHSR was to determine the extent to which currently available data could be used to provide insights into women's health that account for their social and cultural roles and responsibilities. It also aimed to provide policy-relevant information on women's health for use by health practitioners, policy makers, public health officials, non-government organizations, advocacy groups and researchers, as well as to make this information available to the public. We used the findings obtained from large national surveys and databases of health information to explore sex and gender differences in the determinants of health, health behaviours and health outcomes. More than 30 chapters addressed a wide range of issues, including life and health expectancy, disability, chronic diseases, reproductive and sexual health and health-related behaviours. Longer-term goals of the initiative are to evaluate the actual use of the report for decision making in practice and in program and policy development, and to provide a basis for a more comprehensive women's health surveillance system in Canada.

The project was a collaborative effort between the Canadian Population Health Initiative (CPHI), Health Canada, CIHR, Statistics Canada, Status of Women Canada, the Centres of Excellence for Women's Health, university departments and experts and practitioners in women's health across Canada. International collaborators were also involved in the development and review of the report. Funding was provided by CPHI and Health Canada.

The KT initiative

For the WHSR findings to influence policy and practice in women's health, it was necessary to involve as wide a variety of players as possible, both during the research itself and after finalization of the report.

A 14-member steering committee, composed of project partners and multi-sectoral women's health experts, was formed in the first year of project funding. An advisory meeting was held to decide on topics for the report and to select appropriate experts in women's health to conduct the research and write the chapters. The authors were drawn, on the whole, from academic, government, non-government and clinical practice settings across Canada. Each chapter was systematically peer reviewed and three external reviewers evaluated the entire document for overall approach, content and key messages.

In October 2002, once draft outlines and preliminary/sample data results were available for most chapters, we held an external consultation workshop with about forty women's health experts and key stakeholders to gather input on the approach being taken to prepare the WHSR and to elicit suggestions on how best to disseminate and promote awareness of it. Participants, who included medical and public health professionals working in women's health, non-government organizations, policy makers and many others, developed a number of helpful recommendations, many of which were used during the finalization and dissemination of the report.

Our news release highlighting the publication of the report ranked in the top ten accessed files for that day.

The WHSR was completed and released in 2003. We used a comprehensive dissemination strategy, including broad distribution of free printed copies across key national and international organizations; publication in BioMed Central,² an open access, peer-reviewed journal publisher with a wide Internet audience; posting of the entire report on the Public Health Agency of Canada, Health Canada, and Canadian Institute for Health Information websites, as well as links from other partner organization websites; and wide media coverage, including publication of the main findings in *Chatelaine*, a national women's magazine. Our news release highlighting the publication of the report ranked in the top ten accessed files for that day. Collaborating practitioners also actively contributed to dissemination through the distribution of copies of the report in practice settings (e.g. women's health clinics) and through professional organizations.

One of the next steps in continuing the momentum for a sustainable national women's health surveillance system is to evaluate whether the report is a practical and useful tool for women's health policy and program development. Have the recommendations been accepted as valid and are they being acted on? After the active dissemination phase, we gave key stakeholders time to evaluate how the WHSR recommendations could be incorporated into their plans and activities. A survey of stakeholders is currently in the planning phase. We also hope to develop standards to assess whether implementation of the recommendations has the desired effects.

Results of the KT experience

In the WHSR, we presented data from a variety of national administrative and survey databases to investigate sex and gender differences in important areas of women's health. For instance, investigation of the relationship between socioeconomic factors, multiple roles and women's mental health revealed that, irrespective of women's employment status, single mothers are more likely than partnered mothers to be poor and to experience financial stress and food insecurity.

The health topics covered in the WHSR were influenced by the 1998 recommendations of the Advisory Committee on Women's Health Surveillance. Although we acknowledged that political, social and economic

forces are among the most important factors influencing health outcomes, it was not possible to do a comprehensive analysis of these social determinants of health using a gender perspective. This would require data from large follow-up studies designed to more appropriately measure economic and social factors influencing women's health, which are rare in Canada. Participants in the external consultation workshop pointed out that the report was mainly focused on disease and suggested that it be supplemented to make contextual and life issues the basis.

The WHSR findings have now been disseminated to a wide audience. Women's groups and organizations in Canada are making use of the information to continue their advocacy efforts around issues of concern (e.g. women and violence initiatives); those engaged in research are more aware of knowledge gaps to be addressed; and decision makers are in a better position to shape policy in ways that accord with identified needs. The report has stimulated the undertaking of similar efforts specifically targeted at Canadian Aboriginal women and women in the military, and was used by the Federation of Medical Women of Canada to frame the scientific agendas for their last two annual meetings.

Shortly after the release of the report, Alberta's premier announced that a strategy would be developed to address the problem of women and violence. More recently, in her speech celebrating International Women's Week 2005, the Honorable Carolyn Bennett, the Minister of State (Public Health), highlighted the WHSR as one of the important steps that Canada has achieved towards women's equality in the area of health.

The Honorable Carolyn Bennett, the Minister of State (Public Health), highlighted the WHSR as one of the important steps that Canada has achieved towards women's equality in the area of health.

Lessons learned

The interdisciplinary input used to develop the WHSR is essential to the policy development cycle of a sustainable women's health surveillance system. The external consultation provided us with many good ideas on the content, dissemination and use of the report. Some of these were taken up and others have been noted for future reports. For instance, there were suggestions for research on different women's health issues, but reliable data on those topics were not always available. It was also suggested that more consensus around a conceptual framework should have been obtained at the beginning of the research process to guide the choice of topics for the report.

While the collaborative and consultative processes employed in the preparation of the WHSR were invaluable, it was occasionally challenging to reconcile the intended quantitative/statistical approach to the WHSR—i.e. analyzing the available data and attempting to make recommendations on the basis of evidence of effectiveness—with the disciplines and expertise more often found in gender and health research, such as social sciences. In retrospect, there were further steps that could have been taken to prepare the authors, such as short training sessions in the appropriate methods and distribution of a “model chapter” for guidance.

Conclusions and implications

The WHSR presented what is known and, as important, what is not known about many aspects of women's health, together with recommendations for future action. We envision an ongoing knowledge-to-policy cycle, where research and surveillance data guide the process of developing health policy. As a result, in turn, of new policies and their effects, decision makers will be in a position to point to fresh areas in need of surveillance and/or analysis.

The recommendations made in the report for enhancing women's health surveillance and for policy making will be used in the development of future reports; the collaborative networks among researchers, practitioners and policy makers will continue to be active and will be further expanded for evaluation purposes and planning of future activities; agreement will be sought on various conceptual framework approaches to guide the future selection and study of women's health issues; and a core set of gender-sensitive women's health indicators will be developed to monitor and report on progress towards improving women's health in Canada.

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THE GLOBALIZATION, GENDER AND HEALTH PROJECT

Heather Maclean, Centre for Research in Women's Health
Suzanne Sicchia, Centre for Research in Women's Health
Miriam Stewart, Scientific Director, CIHR Institute of Gender and Health
Elizabeth McGregor, former Associate Director, CIHR Institute of Gender and Health
Gloria Bonder, UNESCO Chair in Women, Science, and Technology in Latin America
Zo Randriamaro, Consultant

The Globalization, Gender and Health Project was a large-scale exercise in international research collaboration. Charged with identifying a set of issues at the intersect of globalization, gender and health for future research and training priorities, the team learnt some important lessons on working in international partnerships. Building trust among a diversity of partners from both the developed and developing world was challenging, as was finding broad consensus on priority issues. The payoff has been the establishment of lasting knowledge networks, which continue to support the original research agenda.

Background

In 2002, CIHR's Institute of Gender and Health (IGH), as part of a larger initiative, invited the Centre for Research in Women's Health (CRWH) at the University of Toronto to prepare a background paper on issues at the intersect of globalization, gender and health. The major goals in developing this paper—the Globalization, Gender and Health project—were to engage policy makers, scholars and activists in both developed and developing countries in setting out key issues to help shape a gender and global health research and training agenda and to identify opportunities for future research and partnership.

The project involved many partners, including the National Institutes of Health, the Canadian Coalition for Global Health Research, Harvard University, Yale University, McMaster University, the University of Toronto, UNESCO, the United Nations Development Fund for Women (UNIFEM) and the World Bank. A substantial part of the project involved consultations with collaborators in the developing world. The large-scale integration of expertise from international stakeholders made this project unique and also provided important lessons on working collaboratively in, and structures for, international partnerships—two crucial concepts for effective knowledge translation (KT) in global health.

The KT initiative

Our research began with an extensive literature review of relevant issues, resulting in the drafting of brief issue papers on possible priority topics. These were complemented by an international call for topic-related case studies, with submissions from scholars and service providers worldwide. We then held a series of meetings and regional consultations with stakeholders, which aimed to capture the perspectives of a broad cross-section of scholars, policy makers and government and non-governmental organization (NGO) representatives.

The project design was participatory and iterative. We used snowball sampling to identify individuals from different countries who specialized in relevant areas of research and policy, and we engaged stakeholders by piggybacking focus groups and meetings with existing international forums. We also created small, issue-

We engaged stakeholders by piggybacking focus groups and meetings with existing international forums.

specific think tanks to shape the research process and organized regional symposia with scholars, health professionals, policy makers and donor agencies to learn about region-specific issues. To ensure genuine participation of stakeholders from developing countries, our regional partners led online forums tailored to issues in Latin America and Africa. Each opportunity for input allowed us to refine our background paper and gave us issues to address at future discussions.

Partner agencies took the lead on different components of the project, in addition to providing feedback on the development of the background paper. Partners from developing countries affiliated with UNIFEM and UNESCO designed, implemented and managed the regional consultations. Others participated in planning sessions, provided in-kind technical support, coordinated regional dialogues, organized consultations in tandem with existing international forums and endorsed the project to raise its profile and capture the attention of other potential partners. The IGH Institute Advisory Board served as the steering committee for the entire project.

Extensive use of the Internet, e-mail and teleconferencing, together with face-to-face meetings and a series of symposia, were used to facilitate global dialogue, disseminate study findings, share funding announcements and encourage future collaboration among partner agencies and participants.

Results of the KT initiative

Overall, the project engaged 250 researchers, practitioners and policy makers representing 80 agencies working in gender and global health in more than 30 countries.

We identified eight priority issues (food security and nutrition, HIV/AIDS, occupational health, reproductive health, mental health, addictions, violence and infectious disease) and four special topics (global public goods, migration and health, global health governance and the health of the world's indigenous peoples) at the intersect of globalization, gender and health. Issue papers on each of these topics, which can be used as tools to shape research, training and policy agendas, were included in the background paper, which was widely disseminated in English, Spanish, and French. Other project deliverables, such as a series of articles, papers and presentations on the results of the project, have been circulated via the academic, NGO and government networks of our many partner agencies.

Lessons learned

Over the course of the many collaborations that supported the project, we have learned important lessons about building partnerships and the process of collaboration in global health initiatives.

Fostering trust

Building trust was one of our biggest challenges. While having the support of partners such as the World Bank increased some collaborators' confidence that our findings would inform policy, others were wary of participating in an initiative linked to an agency they viewed as an advocate of unjust forms of globalization. Also, some partners from developing countries felt used by partners from developed countries in the past and so were reluctant to commit their time and expertise to a project sponsored by North American funding agencies. Similar reservations were voiced by some partners from high-income countries who suggested that these kinds of projects went nowhere, eating up resources and making no real difference.

Getting past these barriers required a real effort to listen to and understand the concerns of potential partners and participants. It was important to keep stakeholders informed and allow them to choose their own degree of involvement, but it required a considerable amount of time to keep all 250 collaborators updated on new project developments. We also learned that people who are fully engaged in one stage of the project can feel used if their input is not consistently sought throughout the process. Delays in project deliverables were another potential source of frustration. Maintaining trust is an extremely time-consuming and costly process, and one that continues even now that the project is complete.

Valuing diversity

Definitions of globalization and its impact on health are contested topics and views are polarized. Ideological divisions between stakeholders were deepened by a competitive territoriality over whose knowledge was authoritative. Some partners directly challenged the legitimacy of the knowledge and contributions of others, arguing that they were “too new to global health research” to contribute to a critical understanding of the issues, or questioning the legitimacy of their perspectives. This divisive and competitive climate made building trust and consensus difficult. While we have not found a definitive solution to these problems, helpful strategies included adopting the United Nations definitions of health, gender and globalization, and framing the project in terms of global commitments like the Millennium Development Goals.

Building consensus

Given the breadth of the project’s findings, the funders requested that the research team find consensus on a handful of key issues at the intersect of globalization, gender and health from which recommendations for future research and training could emerge. However, with priorities varying tremendously across and even within regions, finding consensus proved to be a time-consuming and difficult task. Arriving at a core list of issues and recommendations that all partners agreed on also meant that ideas some felt passionately about were lost. Ultimately all members had to compromise. The list of priority issues that emerged was deliberately broad to accommodate as many contributions and as much regional diversity as possible.

With priorities varying tremendously across and even within regions, finding consensus proved to be a time-consuming and difficult task.

Use of technologies

In order to engage international stakeholders, the project relied heavily on information communication technologies (ICTs), including web-based forums, online volunteers,* e-mail, electronic resources and listservs. Using ICTs cost significantly less than the corresponding amount of travel and long-distance phone calls. However, our reliance on ICTs also limited the individuals and agencies that could participate in this initiative, especially colleagues in Africa, where access and infrastructure issues persist. At times, ICTs also posed problems when communications were multilingual.

* The United Nations online volunteering initiative, NetAid, allowed us to work with two exceptional volunteers: George Gopal in Kenya and Sahar Saquib in Afghanistan. This virtual experience was so positive that, in 2003, the CRWH research team successfully nominated one of our volunteers, George Gopal, for the United Nations Online Volunteer of the Year Award.

Reciprocity

A major payoff from the time and energy we put into building trust is the informal support and knowledge networks that this project created among our international collaborators. Regular correspondence among collaborators about funding opportunities, international events and useful resources continues even now that our consultations have ended. The level of collegiality and rapport and the degree of trust that has been built is evidenced by the fact that the research team is regularly approached by collaborators to review grant applications, comment on research proposals and identify potential funding sources or journals or forums where collaborators can present their work. It is important to note that this flow of information is two-way: partners living in industrialized countries are equally likely to seek the expertise and support of colleagues from developing countries.

Conclusions and implications

The success of a partnership or collaboration will always depend to some degree on the mix of personalities involved and on the flexibility of funding agencies.

While some of the lessons we have learned about international collaboration are generalizable, successful collaboration cannot be completely reduced to a single set of standardized “tools”. Rather, as one of our international partners has pointed out, the success of a partnership or collaboration will always depend to some degree on the mix of personalities involved and on the flexibility of funding agencies.

Nonetheless, we hope what we have learned about the time and energy involved in building strong international collaboration helps others conducting research and KT in global health. KT in this area involves a constant balancing of interests, cultures and values. Without attention to the importance of trust, respecting diversity, use of appropriate technologies and ways of giving back, this balance can be destroyed.





OCCUPATIONAL AND
WORKPLACE HEALTH

KNOWLEDGE TRANSLATION THROUGH RESEARCH-BASED THEATRE

Joan M. Eakin, University of Toronto

Marion Endicott, Injured Workers Consultants and the Bancroft Institute

This case documents the metamorphosis of an academic public health project on the implementation of Ontario's return-to-work policies and practices into a community theatre project, the production of a play called Easy Money. The result was a highly successful knowledge translation initiative. Injured workers, the focus of the academic study, intensely identified with the play and were given hope that their individual experiences could be broadly translated. For the researchers, the undertaking provided new perspectives on the original research problem, validated their original findings, and generated numerous topics for subsequent research.

Background

Joan Eakin, with research colleagues Ellen MacEachen and Judy Clarke from the Institute for Work and Health in Toronto, recently completed a study of a new system in Ontario for reducing disability from work-related injury and for getting injured workers back to work.* The system features early return to work (before recovery), modified work (tasks adapted to the injury) and workplace self-reliance (primary self-administration by the workplace parties).

The study identified a number of problematic implications for small workplaces, including the harmful effects for injured workers and for social relationships in the workplace of what the researchers called a “discourse of abuse”, the broadly experienced, institutionalized expectation that workers will misuse the compensation system.

Results of the research were published¹ and presented to other researchers, administrators from the Ontario Workplace Safety and Insurance Board, policy makers, health practitioners and injured workers. The project resulted in a number of tangible outcomes, including change to Ontario's workplace injury reporting form, and invoked exceptional interest from the injured worker community. The success of these initial knowledge translation (KT) efforts prompted us to extend the reach of the study's findings in a novel way: using theatre.

The KT initiative

The use of theatre as a medium of research communication and social change is increasingly recognized.² In Canada's health research arena, the very successful plays of Ross Gray and company³ on the experience of cancer are probably unmatched in terms of reach and impact.

Inspired by these research-informed dramas, and in collaboration with the Injured Workers Consultants (a community legal clinic that had supported the study since its inception) and the Ontario Network of Injured Workers Groups, some funds were scrounged from other research grants to engage an experienced play writer-director. Under her guidance, we secured grants from the Ontario and Toronto Arts Councils and from several labour unions to fund the developmental stage of the project, a period of about one year culminating in the recent first staging of the play *Easy Money*.

* Funded by the Ontario Workplace Safety and Insurance Board.

The purpose of the play is to communicate the research findings to injured workers, system administrators, policy makers, government legislators and the general public, and to involve injured workers themselves in the KT effort. The play was developed incrementally, starting with the writer-director’s reading of the research report and extensive brainstorming sessions with the researcher and the production group about the key research ideas and how they might best be conveyed on stage.

The Injured Workers Theatre Collective—a group of injured workers—was formed through the client base of the legal clinic and met several times with the writer-director to relay personal stories and fuel the scriptwriting. A videographer recorded the storytelling and the participatory process with workers. Seven professional actors,[†] a musician and design specialists were employed to stage the play.

The central motif of the play—a Kafkaesque game of snakes and ladders and the satirical portrayal of injury and compensation as “easy money”—emerged from the confluence of research findings, worker participation and artistic expression. The core analytic concepts and arguments of the research were given artistic expression through dialogue, music, song, movement and stage props.

Results of the KT experience

The play was performed for the first time at the Toronto Mayworks Festival of the Arts in May 2005. Immediately following the show, a discussion was held with the audience (about one hundred people, largely injured workers and their families) to harvest their feedback and ideas for improving the play. Not only were valuable suggestions made about the play, but input from the audience shed new light on aspects of the research analysis and generated new research topics. Planned follow-up activities include adapting the script for general public, service provider and policy maker audiences; producing videos; and sharing the script with other communities for local productions.

The production was hugely successful in terms of the immediate response of the audience. Injured workers identified intensely with the play’s content. Many appeared to feel a sense of being understood for the first time. The use of theatre and professional actors seemed to elevate and legitimize their individual experiences and gave them hope that the institutional systems, in which many felt trapped and ill-served, could be made visible to the public. The response to the play was also validating to the researcher (supporting the “truth” value of the research) and to the community legal partners (as testimony to the effectiveness of their activism).

Lessons learned

What happens to scientific knowledge when it is transformed into art and into vehicles of advocacy and change?

Despite the evident success of the play, it is important to ask questions from the more abstract standpoint of KT.

First, what happens to scientific knowledge when it is transformed into art and into vehicles of advocacy and change? Is science enriched? Dumbed down? De-theorized? In our case, the play had the capacity both to convert abstract research into concrete form and to produce generalizable abstract knowledge from the empirical research findings (i.e. it picked up the generic, universal experience underlying individual stories). Thus, through

[†] Opinions diverge on the pros and cons of using professional actors vs. having injured workers enact their own experiences. In *Easy Money*, the use of professionals contributed significantly to the effectiveness of the play from the injured workers’ perspective by enhancing the perceived social significance of their private experiences.

techniques of metaphor, dialogue and fiction, the characterization of experience in the play was personal and generic, individual and collective, particular and trans-situational.

A related issue stems from the observation that scientifically produced knowledge does not necessarily make “good” theatre or an effective tool for enlightenment or change. Would many people choose to attend a play that focused only on the grim hardships and despair of injured workers? But what happens when research “findings” are altered for theatrical or communicative effect, or when research ideas that are too hard to stage are left out? How does the introduction of humour and irony, for example, relate to the content of the original science? We will undoubtedly learn more about the relationship between science, art and political purpose as we turn to making the play speak to the different audiences of the general public, system administrators, service providers and policy makers.

Second, how should such KT endeavours be appraised, in terms of a return on investment? Whose benefits should be the pivot points of evaluation? In our case, the effectiveness of *Easy Money* as a form of KT could be assessed from multiple standpoints: as a salve and voice for injured workers, as a catalyst for reform among government legislators and administrators, as a source of public pressure for institutional change and as a source of guidance for future research. But can it do all of these without a conflict of interest and political purpose? And is theatre a better vehicle for some purposes than others?

Third, how significant are pragmatic rather than theoretical concerns in KT? Regardless of any abstract theory, its effective execution is deeply contingent upon practical, ground-level resources and considerations. For example, one practical barrier to KT activities can be inappropriate timing and availability of funding. In our case, a restrictive research grant funding policy led to the loss of unspent KT funds that could have been used for the start up of *Easy Money*. Collaboration for creative activities such as this requires more flexible grant arrangements than are often available.

Another practical impediment to KT can be its low value as academic “capital”. Such activities (particularly unorthodox undertakings such as *Easy Money*) may draw researchers into unfamiliar territory that requires time and energy to navigate (e.g. securing funding in the arts arena, learning how plays are mounted) and where the risks and outcomes are unknown. In addition, genuine collaboration can mean, for the researcher, a loss of “control” over the use and interpretation of intellectual property (*quelle horreur* in academia!).

Conclusions and implications

The *Easy Money* experience underscores that KT, a quintessentially collaborative, cross-disciplinary exercise, can only be effective if there is something concrete in it for all partners. It cannot be induced by normative pressure alone (e.g. the belief that publicly funded research *ought to be* useable outside academia), nor even by practical necessity (e.g. KT being required by research funding agencies).

In our case, for the community legal clinic collaborators, *Easy Money* aligned clearly with their organizational mission of improving the lives of injured workers and promoting legislative reform. For the participating injured workers, the play gave voice to personal experience and fostered a sense of meaning and community. For the artists, particularly the writer-director, *Easy Money* was an

KT, a quintessentially collaborative, cross-disciplinary exercise, can only be effective if there is something concrete in it for all partners.

opportunity for political engagement and for a novel experience with community-based theatre. And for the researchers, the undertaking provided new perspectives on the original research problem and significant conceptual fodder for subsequent research. This confluence of interests appeared to be a major factor in making *Easy Money* a KT success story. How successful the play will be in this regard when it is brought to bear on audiences who have different sorts of stakes in the messages and who may not really want to hear them, is a story for a future KT casebook.

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THE AGRICULTURAL HEALTH AND SAFETY NETWORK

Louise Hagel, Institute of Agricultural Rural and Environmental Health, University of Saskatchewan
Helen McDuffie, Institute of Agricultural Rural and Environmental Health, University of Saskatchewan
James Dosman, Institute of Agricultural Rural and Environmental Health, University of Saskatchewan
Lori Lockinger, Institute of Agricultural Rural and Environmental Health, University of Saskatchewan
Julie Bidwell, Institute of Agricultural Rural and Environmental Health, University of Saskatchewan
Sean Siever, Institute of Agricultural Rural and Environmental Health, University of Saskatchewan

Saskatchewan's Agricultural Health and Safety Network is a knowledge translation program aimed at promoting health and safety on the farm through education, service and research. A partnership between the Institute of Agricultural Rural and Environmental Health and the Saskatchewan Association of Rural Municipalities, the Network has grown to serve 26,000 farm families since 1988. The Network's knowledge translation activities include locally delivered education and screening programs to promote awareness of hazards and to identify farmers at risk for occupational injury and illness, and the provision of practical, plain-language educational resources on agricultural health and safety issues.

Background

Farmers and their families are exposed to many different types of potential hazards: pesticides and other agricultural chemicals; viruses, moulds and endotoxins; organic dusts; zoonotic diseases; excessive vibration and noise; and work-related injuries. Research has clearly established an increased incidence of certain adverse health outcomes (respiratory diseases, selected cancers, deafness, injuries) associated with occupational and environmental exposures in this population when compared to their non-farming counterparts.

The Agricultural Health and Safety Network is a knowledge translation (KT) program aimed at preventing occupational illness and disability in Saskatchewan farmers. It was established in 1988 as a joint initiative between the Institute of Agricultural Rural and Environmental Health (formerly the Centre for Agricultural Medicine), a research unit at the University of Saskatchewan, and the Saskatchewan Association of Rural Municipalities, to translate the Institute's research results into practical, useful information for farmers.

The Network is committed to informing farmers, their families and workers in related industries about potential hazards in their workplaces and management practices which reduce their exposures. Using research findings from our own studies, as well as national and international research, we design, implement and evaluate health information and services for farm communities, in collaboration with producers and various types of experts located within numerous agencies.

The KT initiative

The evolution of the Network has been a study in cooperation, creativity, imagination and determination. Our staff, who are located at the Institute of Agricultural Rural and Environmental Health, engage in communication and consultation activities with a variety of stakeholders, including farmers, their families, researchers, policy makers and rural volunteers, to develop and implement techniques to improve the health and safety environment in all aspects of the agricultural industry. Each partner contributes time, expert knowledge, funds and in-kind support in a collaborative, interactive manner.

Membership in the Network is voluntary and subject to an annual fee paid by municipal councillors on behalf of their resident farming families. Membership fees are then used as matching funds for grant applications and to support the development of materials and provision of services to Network members. The Network typically employs one staff nurse to deliver programs, coordinate activities, communicate with members and assist in the development of educational materials.

The Network has active steering and advisory committees whose farmer and agricultural professional members generate new ideas, communicate producer concerns and provide guidance in the use of language and KT techniques for various sectors of the agricultural community, as well as to policy makers and health professionals. The Network also has volunteers, including academics, farmers, occupational health professionals, public health professionals and policy makers, who review, test and evaluate proposed programs, documents, and interventions. The success of the Network is substantially enhanced by the willingness of these volunteers to donate their time, expertise and resources to a cooperative effort.

The Network provides a number of key education and screening programs for farmers and their families, including the Respiratory Health Maintenance Program and the Hearing Conservation Program, which are delivered by trained staff in the local community and include physician follow up, if necessary. The programs

The Network offers an accident preparedness course, which teaches farmers and family members what to do in the event of a farm emergency.

aim to increase awareness of hazards, promote methods to reduce exposures and identify farmers at risk for occupational injury and illness. We also offer an accident preparedness course, which teaches farmers and family members what to do in the event of a farm emergency.

The Network sponsors and coordinates regular and annual meetings, seminars, workshops and summits and provides display booths and presentations in communities across Saskatchewan. We host a farm injury control summit for producers, health and safety professionals and government policy makers each year. The summit is committed to decreasing the frequency and severity of injuries on the farm and we have developed and recommended policy changes for governments, farmers, farm managers and farm families. In 2005, for instance, the summit focused on sleep deprivation and stress as antecedents of farm injury

incidents, and provided up-to-date information on coping techniques. Farmer-invented safety devices are also often featured. The Network staff are also active participants in local, provincial, national and international organizations that have a focus on agricultural health and safety through initiatives related to health promotion, educational activities, injury surveillance and targeted research.

We also provide fact sheets, Power Point presentations (which are developed, tested and made available to local speakers), booklets and videos to Network members and distribute annual educational packages on topics such as farm safety audits to farm families. Network members receive a newsletter twice a year to provide them with health and safety information and to keep them updated with Network activities and programs. We also use the print, television and radio media to advertise events, publicize research findings and promote safety messages. Rural and agricultural newspaper editors, for example, provide deeply discounted rates for publishing our material.

We have formal and structured evaluation strategies, including questionnaires, peer-reviewed grants, active advisory committees and student assessments of the economic sustainability of various initiatives. We actively solicit communication with our farm families by telephone, e-mail, fax, mail and in person. Each item that we

distribute carries how-to-contact information and reply postcards are included in all publications. Our most impressive evaluation, however, is undertaken by the six municipal council members in each of the 154 rural municipalities who decide that maintaining health and safety practices is a priority for their actively farming families each year.

Results of the KT experience

The Network has increased from five to 154 rural municipalities, and from 1,000 to 26,000 farm families, representing more than half of all farms in Saskatchewan, since 1988.

Growth of the Network has been sustained in spite of the challenges of a strained agricultural economy and has increased from five to 154 rural municipalities, and from 1,000 to 26,000 farm families, representing more than half of all farms in Saskatchewan, since 1988. There has been reported evidence of an increase in awareness of farm health and safety issues and behavioural changes in response, but little quantification on a provincial basis.

Lessons learned

The Network has taught us a number of important KT lessons over the years. The Network evolved out of an identified need and a natural partnership between a research unit engaged in agricultural health and safety and the Saskatchewan Association of Rural Municipalities, which already had a rich history of advocating for the health and safety of agricultural producers. A clear vision of the issues to be addressed, coupled with dedicated and committed partners, can sustain a diverse, long-term partnership. The Network has survived and indeed, flourished, because of the

trust between partners, the free flow of knowledge and a shared responsibility for program planning and development.

When the Network began, we knew that farmers wanted practical information from a reliable source provided to them in a convenient way. One of our first challenges was figuring out how to deliver information to the farm gate in an appropriate format, and we quickly learnt that farmers wanted more than printed materials. Our mobile screening and educational programs grew out of this expressed need, and also provided new opportunities for personal contact with Network members, which was becoming an increasing challenge as the Network grew. This speaks to the importance of communication and active listening with research users, and being flexible and willing to adapt initial KT approaches in response.

The Network has survived and indeed, flourished, because of the trust between partners, the free flow of knowledge and a shared responsibility for program planning and development.

In delivering these mobile programs, partnering with local councils was crucial. The support of respected local leaders was seen as testimony to the value of the program and encouraged participation. The success of the programs, as evidenced by good attendance and positive feedback, in turn creates a sense of community ownership in the program and in the wider Network.

In a province as large and geographically diverse, from an agricultural perspective, as Saskatchewan, the Network remains grossly understaffed. As our membership increases, it is increasingly difficult to deliver services in proximity to the farm gate and to collect, collate and disseminate producer ideas on topics such as health and safety practices, insurance and innovations to policy makers in a timely fashion, and to respond quickly to new initiatives.

The response to these challenges has been typically rural: the persistence and dedication of committed volunteers from academia, agriculture and government; the development of creative fundraising; and learning to accomplish a lot with limited resources.

The response to these challenges has been typically rural: the persistence and dedication of committed volunteers from academia, agriculture and government; the development of creative fundraising; and learning to accomplish a lot with limited resources.

Conclusions and implications

The challenge of developing and delivering targeted and effective prevention programs to producers in a wide geographical area remains. Models for successful program delivery at or near the farm gate have been developed, evaluated and standardized by health professionals in collaboration with producers, researchers and policy makers. We now offer professional health training days for public health nurses in partnership with all of the health regions, and provide resources on health and safety in agriculture for the nurses to use as part of their practices. However, the rapid alteration of the rural landscape continues to provide new challenges and opportunities to ensure the health and safety of farmers and their families.



THE QUEBEC NETWORK FOR WORK REHABILITATION: THE CHALLENGE OF KNOWLEDGE TRANSLATION AND IMPLEMENTING A PROGRAM IN CLINICAL PRACTICE

Patrick Loisel, MD, Université de Sherbrooke
Josée Labelle, MSc, OT, Université de Sherbrooke

The Quebec Network for Work Rehabilitation (RRTQ) was founded in 2001 to develop and implement evidence-based prevention and rehabilitation programs aimed at getting injured workers back to work more quickly. The RRTQ also aimed to foster the development of new knowledge and practices in work rehabilitation through research and training. While a pilot implementation study of an evidence-based program at four rehabilitation institutions was generally successful, significant opposition to the mandated nature of the program implementation arose among certain partners. Funding for the network was not renewed, highlighting the crucial importance of involving all parties in each stage of the knowledge translation (KT) process.

Background

In Quebec, as in many industrialized countries, work-related musculoskeletal disorders (MSDs) are common and costly. The most recent data in occupational health suggest a growing awareness that rehabilitation programs targeting MSD disabilities in workers must adopt a comprehensive approach to the problem, taking into account workers' actual work environments (workplace, compensation programs, health care system and respective parties).^{1,2} Yet the establishment of such programs can encounter obstacles related to the differing perspectives and stakes involved for the concerned parties (workers, health professionals, rehabilitation counsellors, employees and unions). Research on collaboration may lead to answers to these kinds of difficulties.

In a randomized clinical trial, Patrick Loisel and his team have developed and tested the Sherbrooke model³, a rehabilitation program promoting an integrated approach directed at both workers and the workplace. Based on the results of this trial and ten years of experience in the field, they took the first steps towards creating a provincial public health network in work rehabilitation. From that point on, various public agencies expressed interest, and a formal interagency alliance was born in Quebec.

In 1999, an outreach plan for a work rehabilitation program was presented to the board of directors at the Commission de la santé et de la sécurité du travail (CSST), the agency in charge of administering Quebec's workplace health and safety plan (Régime québécois de santé et de sécurité au travail). In December 2000, the CSST decided to give start-up support to the Quebec Network for Work Rehabilitation (Réseau en réadaptation au travail du Québec (RRTQ)) by conducting a pilot implementation study for the work rehabilitation program in four RRTQ partner institutions (Hôpital Charles LeMoine, Centre de réadaptation La Maison, Centre de réadaptation Lucie-Bruneau and the Institut de réadaptation en déficience physique du Québec). The CSST allocated funding to cover the costs of rehabilitation services and network coordination. Through this partnership, RRTQ brought together the public health network and a research team at Hôpital Charles LeMoine and Université de Sherbrooke, making both groups available to employers, unions and the CSST in an effort to help them reduce the incidence of work-related musculoskeletal disabilities.

The KT initiative

RRTQ was formally founded on October 1, 2001 as a horizontal network representing a consortium of ten public rehabilitation institutions and one hospital mandated for rehabilitation in Quebec. The mission of the RRTQ was to:

- Prevent prolonged absences from work by developing and implementing evidence-based prevention and rehabilitation programs for individuals and companies; and
- Foster the acquisition of new knowledge and practices in work rehabilitation through research and training.

The first program implemented by the RRTQ was PRÉVICAP^{4,5}, a rehabilitation program based on the results of the Sherbrooke model study. The program was for the rapid, long-term and safe return to work of injured workers by emphasizing a type of rehabilitation that progressed gradually from the clinical setting to the workplace. PRÉVICAP targeted workers whose persistent pain rendered work difficult or impossible, but for whom a return to work remained the objective.

During the thirty-month pilot study, interdisciplinary teams composed of program coordinators, occupational therapists, physical educators, physicians, ergonomists and physiotherapists were set up in each of the four rehabilitation institutions. Each team received theoretical and practical training on the program itself and on the latest available evidence on work rehabilitation. To reinforce this training, the director of the RRTQ visited pilot locations, training seminars were given via videoconference, and a professional development symposium was held, bringing together clinicians from all four institutions.

Implementing the PRÉVICAP program required collaboration with CSST personnel, who were asked to refer all workers who met the eligibility criteria to the teams at the four institutions in the pilot study. In addition, RRTQ management, in cooperation with project heads from the CSST consultants branch, provided training for managers and rehabilitation counsellors from each participating regional branch of the CSST involved in the trial. To foster early referral for injured workers, discussion and information-sharing sessions were organized between clinicians and CSST managers and counsellors.

Three committees were formed to supervise the development, coordination and follow-up of program implementation activities in the rehabilitation institutions:

- The executive committee (all institution directors general, as well as the director and assistant director of the RRTQ) was mandated to propose the structure and operating procedures for the consortium, to administer the consortium, and to take charge of negotiations with funding organizations;
- The steering committee (clinical directors, program heads or clinical managers from the institutions and the director and assistant director of the RRTQ) ensured that RRTQ programming activities were properly coordinated and harmonized; and
- The coordinating committee (program coordinators from the four institutions of the pilot project and the director and assistant director of the RRTQ) supervised program management and implementation.

In addition to these committees, a project information and management system (IMS) was created to enable the director to keep a close watch on interventions with workers, as stipulated in the agreement, to ensure adequate team counselling. The IMS also allowed the director to monitor project progress and provide the CSST with regular updates. Lastly, a website was developed, detailing the structure of the RRTQ and describing its operations, members, clinical program, and research and training

activities. As well as informing the general public about the network, this website was also used to disseminate new evidence on work rehabilitation to clinicians.

Results of the KT experience

Generally speaking, program implementation progressed well within the four rehabilitation institutions. Interdisciplinary teams were put into place, as planned, and expertise was developed and shared. As of December 31, 2003, 501 workers had been referred by the CSST, and 437 workers who met the eligibility criteria had been assessed by RRTQ teams. For 259 of these eligible workers, a joint decision was made between the worker, the PRÉVICAP team, the CSST rehabilitation counsellor and the attending physician to participate in the rehabilitation program, which was done. The rate of return to pre-injury work was 62%, with an overall average of 24 full weeks away from work.

One obstacle we encountered during program implementation was the low number of eligible referrals, which fell below the original CSST projection (437 instead of 630). We believe that this difficulty may be attributed to resistance to the project from the rehabilitation counsellors. A number of reasons may explain this: a feeling that decision-making independence was being threatened, an impression that workload was increasing through collaboration with clinical teams and a fear of role conflicts and job losses. In June 2003, faced with these difficulties, CSST management announced that it did not plan to renew the agreement with the RRTQ at the expiry date, which had already been brought forward from April 2004 to December 31, 2003.

Thus, the RRTQ ended its activities in December 2003. The program was not implemented in the remaining institutions, as it had been planned. Moreover, only two of the four pilot study institutions are still offering the PRÉVICAP program. With no funding and no guarantee of a sufficient number of referrals, these institutions cannot maintain interdisciplinary teams for this program alone.

Lessons learned

One lesson we learned from this experience in KT is the importance of involving all partners, at all hierarchical levels and in all institutions affected by a project, in the planning and implementation process. Acting against the will of CSST personnel did enormous damage to the RRTQ implementation process. For example, while participation by clinicians was voluntary, all of the

It would have been preferable to involve CSST personnel in program development and implementation, so that they could better understand their role in the program.

managers and rehabilitation counsellors from participating regional branches were required to refer workers meeting the inclusion criteria to teams applying the PRÉVICAP program. Yet managers and rehabilitation counsellors typically enjoy a great deal of independence in their duties, such that imposing this constraint on them generated strong opposition to the program. It would have been preferable to involve CSST personnel in program development and implementation, so that they could better understand their role in the program and be reassured about their responsibilities. Furthermore, collaboration with the CSST in

Acting against the will of CSST personnel did enormous damage to the RRTQ implementation process.

implementing the project took place through the consultants branch, which holds an advisory role in program development and training, rather than a hierarchical role with personnel who must collaborate with clinicians. Within the framework of pilot project implementation, involvement with the operations branch, which maintains a leadership role with rehabilitation counsellors, would probably have allowed us to better identify potential difficulties and work to prevent them.

Conclusions and implications

Even though the RRTQ no longer exists, one result of the consortium is that clinicians are now more aware of the importance of updating their knowledge about workplace health and safety. Since the demise of the RRTQ, we have received several requests for training from clinicians and rehabilitation institutions.

Implementing a complex, evidence-based rehabilitation program within an organization requires involvement from all personnel, particularly from those who will be directly responsible for undertaking the interventions.

Implementing a complex, evidence-based rehabilitation program within an organization requires involvement from all personnel from the development phase onward, particularly from those who will be directly responsible for undertaking the interventions. On the basis of the RRTQ experience, we recommend that no broad implementation effort be undertaken without prior agreement from everyone involved.

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INTERPROVINCIAL KNOWLEDGE TRANSLATION IN OCCUPATIONAL HEALTH AND SAFETY

Robert Parent, PhD, Université de Sherbrooke

Barbara Neis, PhD, Memorial University of Newfoundland and co-director, SafetyNet

Alain Lajoie, Institut de recherche Robert-Sauvé en santé et en sécurité du travail

Mario Roy, PhD, Université de Sherbrooke

Stephen Bornstein, PhD, Memorial University of Newfoundland and co-director, SafetyNet

Lise Desmarais, PhD, Université de Sherbrooke

Scott MacKinnon, PhD, SafetyNet Research Chair in Workplace Health and Safety

The Eastern Canada Consortium on Workplace Health and Safety supports workplace health and safety research and its application to real-world settings. With a focus on creating research capacity in Atlantic Canada and Quebec, the consortium's major knowledge translation activities include the translation of Quebec success stories to Newfoundland and Labrador and a learning history approach to help the consortium overcome challenges posed by its multi-sectoral, multi-province, bilingual membership. The consortium's experience points to the crucial role of capacity—the ability to generate, disseminate, absorb and adapt to new knowledge—in the success or failure of knowledge translation initiatives.

Background

Annual industrial health and safety costs in Canada are estimated at more than \$10 billion, and hundreds of thousands of employees are involved in industrial accidents each year. Many more carry the burden of occupational diseases.¹ Yet research on the causation and prevention of workplace injury and illness is relatively underdeveloped in Canada, when compared to countries such as Sweden, Norway, Germany and France. In addition, regional disparities in research capacity and limited knowledge translation (KT) among provinces hinder the implementation of known prevention strategies. Canada's Atlantic provinces are particularly lacking in research capacity in workplace health and safety (WHS) and in the human and other resources needed to facilitate the routine translation of research findings into the region.

The Eastern Canada Consortium on Workplace Health and Safety was established to redress these problems by supporting research initiatives related to the creation of new WHS knowledge and its translation from the research setting to real-world applications. It is a multi-site, multi-province, bilingual venture designed to enable researchers in Quebec and Atlantic Canada to do interdisciplinary work on the analysis and prevention of injuries and occupational disease in the workplace, and to get the results of new and existing research into the hands of decision makers and workplaces. A central focus of the consortium's research is looking for ways to overcome the barriers to successful WHS KT.

The consortium is funded by CIHR, the Memorial University of Newfoundland, Université de Sherbrooke, l'Institut de recherche Robert-Sauvé en santé et en sécurité du travail (IRSST)—a major Canadian workplace health and safety research institute in Quebec—and INCO, a global nickel mining company. The three organizational members of the consortium are SafetyNet, a Community Alliance for Health Research in Newfoundland and Labrador (NL), the IRSST and the Centre d'étude en organisation du travail (CÉOT), a Quebec-based university research centre specializing in knowledge transfer.

The KT initiative

A major KT activity for the consortium is identifying research-based success stories in Quebec, with its long established traditions of university-government-workplace collaboration, and translating those to NL researchers, community partners and workplaces. These “quick hit” projects help promote WHS in a particular sector and build receptor capacity for research products within the WHS leadership in NL. From the KT perspective, the thinking, borrowed from change management literature, was that this approach would help us learn how to successfully translate WHS knowledge from one province to another and generate early success stories upon which to build support for other KT activities and for local research among WHS leaders in NL.

From a list of successful research projects and products from Quebec, consortium members identified an initial list of eleven potential quick hits in conjunction with WHS leaders in NL. However, we ran into difficulty because some didn’t necessarily respond to perceived needs in the practitioner community: successful KT requires considerable buy-in (including in-kind and financial investment) from local groups. On the advice of

We converted from a “push” to a “pull” approach, by identifying and building interest in KT with community organizations before jointly identifying potential quick hits with them.

our advisory committee, we therefore converted from a “push” (“pushing” Quebec examples into NL communities) to a “pull” approach, by identifying and building interest in KT with community organizations before jointly identifying potential quick hits with them.

One example of this involved the Newfoundland and Labrador Construction Safety Association (NLCSA), the largest WHS sectoral association in Newfoundland and the only association to operate in a similar fashion to the one in Quebec. SafetyNet facilitated interprovincial networking between the two associations and, through this process, two Quebec research products were identified. We are now in the process of translating these products for use in WHS prevention within the Newfoundland industry. This approach resulted in longer timelines for the projects, but reduced the overall costs and increased their likelihood of success.

As a second example, one quick hit project, a “train-the-trainer” model knife sharpening and honing program, was initially anticipated to be relatively simple to transfer to NL meat and fish processing factories. However, this also proved to take longer than planned because of financial implications. Two companies were interested in the program, but neither organization was able to pay the full costs associated with the transfer. The companies partnered with SafetyNet in a successful funding application to the Workplace Health, Safety and Compensation Commission of Newfoundland and Labrador, and the fully funded project is about to get underway.

The second major activity of the consortium is a KT effort aimed at judging the success of the consortium itself, and monitoring and improving communication among its members. We use a “learning history”—a document or series of documents disseminated in a way that helps systems, individual participants and organizations become better aware of their own learning and change efforts.² The learning history presents the experiences and understanding of the participants, including the people who initiated, implemented and participated in organizational transformation efforts, and those who did not participate, but were affected by these efforts.

Results of the KT experience

As a result of the consortium’s KT activities, we have concluded that effective health and safety KT requires a system or network of stakeholders who work together to produce desired results. This is in sharp contrast with many early KT models that generally viewed knowledge as something (an object) that could be passed on mechanistically from the creator to a user. This implies a hierarchical, top-down relationship between the generator of knowledge and the user, and has been criticized for ignoring the reality of both the context within which the knowledge was generated, and the one within which it will be used.^{3,4}

KT capacity within the entire social system or network can make the difference between success and failure of the translation.

More recent attention on KT has focused on it as a process. Szulanski, for example, investigated the role of both the context of KT and the characteristics of the knowledge being translated, and found that most of the difficulties with KT emanated primarily from the receiving unit.⁵ Our experience in a broad variety of organizational settings, ranging from highly creative health and safety research organizations to more practical health care provider settings, supports Szulanski’s view of the importance of receptor capacity. However, this case study also indicates that, in addition to context, KT capacity within the entire social system or network can make the difference between success and failure of the translation.

Our quick-hit exercises highlighted that the major difference between the KT situation in Quebec and NL is that the Quebec WHS network is mandated by laws that specify roles and responsibilities for different stakeholders and has formalized coordinated activities. In NL, the WHS network is more informal and less coordinated, and has fewer direct financial incentives for employers to invest in KT. In order to translate knowledge from Quebec to NL, therefore, the consortium had to find ways to strengthen the WHS network within NL, and also to build new relationships between Quebec and NL. Through the efforts of the consortium, an integrated network of capacities is now beginning to emerge.

Lessons learned

Many lessons can be drawn from the first two years of the consortium’s work on quick hits:

- A push approach to KT—“pushing” successful Quebec examples into NL communities—was less successful than a pull approach that identified needs within the NL community and looked for appropriate solutions developed in Quebec. In other words, our initial focus had been on the success stories in Quebec that could help in NL, as opposed to a focus on the needs in NL that products from Quebec could address.
- Quick hits reinforced the need to focus on the strengthening of the system or network of stakeholders. Those systems or networks need to possess specific capacities for KT to succeed, including the capacity to generate, disseminate, absorb and adapt to new knowledge.
- Quick hits may not necessarily be quick or obvious, but they contribute significantly to the formation of the system or network required for KT to succeed.

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While still in the preliminary stages, our assessment of the learning history methodology is that it will provide an invaluable history in the participants' own words of what worked and what didn't throughout the project. It offers an additional diagnostic tool for the consortium leadership to quickly address issues that may become problematic to the success of the project, and will provide us with a well-grounded understanding of what to do and not to do in similar situations in the future. While it is time consuming, it also serves as an excellent source of information for future articles and case studies about the project.

Conclusions and implications

Members of the project are currently developing a KT capacity model that will elaborate on the capacities required for successful KT. While recognizing the value of past research, we believe that the study of capacities provides a valuable new lens through which to view KT and holds enormous promise for new research on, and application of, KT capacities in a knowledge-based economy.

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TRANSLATING RESEARCH KNOWLEDGE TO STAKEHOLDERS: THE CASE OF FORKLIFT SAFETY

Jean Guy Richard, Institut de recherche Robert-Sauvé en santé et sécurité du travail

Steeve Vigneault, Institut de recherche Robert-Sauvé en santé et sécurité du travail

Lise Desmarais, Université de Sherbrooke

Robert Parent, Université de Sherbrooke

This initiative was aimed at strengthening knowledge-sharing capacities between researchers at Quebec's Institut de recherche Robert-Sauvé en santé et sécurité du travail (IRSST) and stakeholders mandated to implement Quebec's occupational health and safety legislation. The project was initially focused on the complex research required to assess the effectiveness of safety devices for forklifts, with knowledge translation limited to dissemination of scientific findings. When the people in charge learnt the stakeholders were not getting the answers they required, they invested in a knowledge transfer officer and focused knowledge translation activities on capacity building, greatly improving the effectiveness of the project.

Background

In 1990, Quebec's chief coroner noted a high rate of fatal workplace accidents involving forklifts (fourteen accidents during the preceding five years, with several caused by the forklift rolling over), and ordered an inquiry into the risks associated with operating this type of vehicle. Similarly alarmed, the Commission de la santé et de la sécurité du travail (CSST), the agency in charge of administering Quebec's workplace health and safety plan, and several other prevention-oriented joint sector-based associations, asked the Institut de recherche Robert-Sauvé en santé et sécurité du travail (IRSST) to look into the issue of protection for forklift operators in cases of vehicle rollover.

During its preliminary studies, the IRSST researchers noted that a great many safety devices for forklifts already existed. They surmised that the challenge would be to determine the varying effectiveness of these devices so that regulations could be adapted (for example, to require the installation and wearing of safety belts). The stakeholder parties wanted researchers to settle the issue on the basis of scientific evidence, much as similar research had given rise to regulations on the wearing of seat belts in automobiles. The IRSST agreed to take up the challenge, in collaboration with the Institut national de recherche scientifique (INRS) in France. A total of five teams would utilize ergonomics, modelling and digital simulation tools to better understand the risks of rollover and collision to help improve workplace design and, subsequently, issue an opinion on the effectiveness of protective devices for forklift operators.

The KT initiative

The IRSST places a great deal of importance on translating the results of the research it funds into changes in workplace settings and improvements in workplace health and safety (WHS). For the IRSST, it is essential to go beyond simple knowledge dissemination: capacities must also be in place for translating that knowledge into action. This project therefore focused on strengthening knowledge-sharing capacities between the IRSST researchers and the stakeholders mandated to implement Quebec's occupational health and safety network.

The capacity-based dynamic knowledge transfer model developed by the Knowledge Transfer Research Laboratory (Laboratoire de transfert des connaissances) at the Université de Sherbrooke suggests that the

effectiveness of the knowledge translation (KT) process is closely tied to four capacities: knowledge generation, dissemination, absorption and adaptation. Generation is the capacity to create new knowledge. Dissemination is the capacity to distribute that knowledge. Absorption refers to the user's ability to see the value of that new knowledge and use it to change behaviour. Finally, adaptation is the ability to continuously learn and keep pace with changing situational needs. As a result, one hypothesis that may explain the initial failure of KT between researchers and practitioners in the forklift project could be the fact that at the beginning of the project, only one capacity—knowledge generation—was put into play. No specific attention was placed on the other three capacities.

As a result of this, our KT strategy evolved, starting with knowledge production and dissemination via research reports and scientific communications, and moving towards activities to identify and formalize needs and share knowledge arising from both the research community and WHS stakeholders. This shifting of effort towards the development of absorption capacities found its best expression in activities analyzing the practices and experiential knowledge of stakeholders (mainly work inspectors and prevention counsellors).

Results of the KT experience

At first, exchanges with the stakeholders consisted only of research follow-up committee meetings, which were conducted by researchers and focused mainly on knowledge generation and dissemination. The result, after six years, was that the stakeholders felt that they were not obtaining satisfactory answers to their requests, despite the high quality of the research. Among other things, this led to misunderstandings among the main project players, in addition to some stakeholder dissatisfaction.

The researchers argued that they needed more time, given the complex nature of the problems under investigation (the effectiveness of restraining devices and their impact on lift operators' activities) and the need to provide stakeholders with scientific evidence. On the other hand, legislators and workers were losing patience with the lengthy process, and pointed out that as they waited for results, lift operators went on dying. The project was suffering from the absence of two capacities: knowledge absorption and transfer strategy adaptation.

Faced with the extreme complexity and diversity of the needs expressed by stakeholders and workplaces, and discovering that only a fraction of expectations would be met by the research, despite the substantial resources devoted to it, the IRSST redefined its strategy, investing in a resource person to foster exchanges and facilitate communication within the researcher-user network. In addition to continuing knowledge generation and dissemination activities, considerable effort was directed towards analyzing the contexts and procedures for acquiring and utilizing this knowledge (absorption and adaptation capacities). This was expressed by:

- Engaging in technical and scientific intelligence gathering, including the preparation of a data base and the release of information to stakeholders. This utilization of all knowledge available in the scientific and technical literature made it possible to produce bulletins on a regular basis, either electronically or using various types of summary statements;
- Analyzing needs and knowledge utilization procedures for stakeholders via interviews, participation in training, workplace tours, presentations in regional prevention groups, etc.;
- Creating and conducting an exchange forum that brought together the principal stakeholders; and
- Presenting various summaries of the knowledge acquired during the preceding activities to the research follow-up committee and researchers.

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Experience has shown that when researchers know more about realities in the field, research results are often more effective. Giving researchers access to the experience of practitioners responsible for the dissemination and absorption of new knowledge enriches their research experience and enables them to tailor the presentation of their results to best match the absorption capacity of research users.

Lessons learned

This research project and its accompanying KT activities led us to make several discoveries. The three most important lessons are listed below.

1. Constant effort must be exerted in conducting KT in encouraging exchanges and in forging links. From this perspective, the role of the transfer officer is to relay information in both directions: not only from research towards other stakeholders but also from stakeholders towards research.
2. The effectiveness of KT depends upon the degree of understanding of needs and operational procedures prevailing in each of the three following universes: research, intervention and decision-making. It is important to be familiar with the other party's work, context, needs and KT capacities. Those responsible for KT must be able to circulate freely among various spheres and foster interactions. They must be able to explain research limitations and possibilities, help prioritize needs, identify what is relevant for public release and in what form, format information and supervise the path knowledge takes, right down to its implementation in various work settings.
3. Transfer or exchange officers build their own knowledge based on practice. By doing this, they become experts in the sectors in question and can thus provide information to both the researcher and stakeholder communities. An analysis of this new way of functioning in KT illustrates the challenges that must be taken up by parties involved in research activities: in this case, researchers, who want to meet the needs of WHS decision makers and practitioners, and the practitioners themselves, who need to acquire this scientific knowledge and convert it into action. A third party—the transfer officer—has greatly improved exchanges between these two other spheres and, by doing so, has increased the effectiveness of research, a crucial component in improving health and safety in the workplace.

Constant effort must be exerted in conducting KT in encouraging exchanges and in forging links.

Conclusions and implications

The KT activities associated with this project enabled us to create a database for use by health and safety researchers and practitioners. This also contributed to creating our dynamic approach to information sharing, which increases the return on investment in research. The transfer or exchange officer is now playing a key role on this project, leading to numerous requests for collaborations in the production of technical and educational material. The emergence of such requests is an excellent measure of the success of these initiatives and requires that we adapt our KT strategy once again. The results obtained on this project, among others, are now informing an in-depth review by the IRSST's management team of its global strategy to improve the use of research findings.





INFECTIOUS AND
CHRONIC DISEASES

ONTARIO'S ASTHMA PLAN OF ACTION: BRIDGING THE GAP BETWEEN KNOWLEDGE AND PRACTICE

Nancy Garvey, Asthma Program Coordinator, Ontario Ministry of Health and Long-Term Care

In 2002, the Ontario Ministry of Health and Long-Term Care announced \$4 million in annual funding for the province's Asthma Plan of Action, an integrated strategy of 13 initiatives, based on the Canadian Asthma Consensus Guidelines and the Canadian Thoracic Society guidelines for occupational asthma. Extensive partnerships involving researchers, clinicians, community-based organizations and policy makers have been formed to develop, implement and evaluate these pilot initiatives. Initial evaluations demonstrate noticeable improvements in uptake and practice of the asthma guidelines and will ultimately contribute to a broader provincial plan for asthma in Ontario.

Background

Asthma is one of the most common chronic conditions in Canada. Over the past two decades, the prevalence of asthma has risen markedly in Ontario and around the world. This increase is particularly evident among school-aged children, with approximately 12% of children, and 7% of adults, in Ontario being diagnosed with asthma. Asthma is the leading cause of hospitalization for children in Ontario and is a significant cause of school and work absenteeism.¹

In 2000, following recommendations from an inquest into the death of a young asthmatic, Ontario's Ministry of Health and Long-Term Care called together an expert panel steering committee and three working groups to provide advice for a phased approach to a provincial asthma strategy. Their recommendations resulted in an evidence-based plan—the Asthma Plan of Action (APA)—that supports best practices for addressing asthma across a variety of practice settings and community environments, where people with asthma live, learn, work and play.

In January 2002, the Ontario Ministry of Health and Long-Term Care announced \$4 million in annual funding for the APA, an integrated strategy of 13 initiatives, based on the Canadian Asthma Consensus Guidelines^{2,3} and the Canadian Thoracic Society Guidelines for occupational asthma.⁴ The goal of the APA is to reduce mortality, morbidity and health care costs for children and adults with asthma through integrated initiatives focused on health promotion and prevention, management and treatment and research and surveillance. Pilot projects are scheduled for completion in March 2006.

A unique feature of the APA is the partnerships that have been formed to develop, implement and evaluate these pilot initiatives. Four Ontario ministries, five public health units, five municipalities, 12 school boards, nine primary care sites, 12 non-governmental agencies and researchers from four Ontario universities, as well as the Institute for Clinical Evaluative Sciences, have been engaged for the pilot project phase. Each of the 13 initiatives is guided by an advisory committee that solicits input for development, implementation and evaluation from participants, front-line health care providers and researchers.

The KT initiative

The APA uses a trans-disciplinary approach, bringing researchers, clinicians, representative agencies and policy makers together to integrate their varied perspectives into relevant programs and services. Behavioural change for patients, providers and targeted audiences—such as teachers and school staff and agricultural and industrial

workers—is supported through dissemination and implementation activities related to the asthma guidelines. Specific knowledge translation (KT) activities designed to promote guideline uptake and research capacity include needs assessments, multidisciplinary pathways, self-management programs, small group case-based learning and community- and media-based programming.

The initiatives include an asthma care program to support best practice in primary care; numerous school-based asthma education programs aimed at supporting children in successfully managing their asthma; community-based educational campaigns to address second-hand smoke in homes and cars; awareness-raising initiatives for occupational asthma in high-risk industries and agriculture; a standardized emergency management pathway for adult asthma; provider education for asthma and occupational asthma; asthma education materials for patients and providers; and asthma and occupational asthma surveillance projects.

One key APA initiative targeting individual patients and their families is the Primary Care Asthma Pilot Project (PCAPP), which is designed to facilitate KT of asthma guidelines in primary care settings through the Asthma Care Program (ACP). The ACP was developed in collaboration with the Ontario Thoracic Society, the PCAPP Design Task Force and the research team. The ACP includes an asthma care map, action plan, flow chart and generic program standards. The asthma care map prompts the use of objective measures for diagnosis, monitoring, environmental control/trigger avoidance, self-management, medication, education and regular assessment of control parameters in accordance with the asthma guidelines. Education materials are reviewed and approved by the PCAPP Task Force, which includes administrative and clinical representation from each primary care setting. Nine primary care sites, encompassing 16 locations across Ontario, are involved in the project.⁵

The ACP was introduced to each site by way of a second, linked initiative called the Provider Education Project, aided by orientation by an onsite coordinator. In the Provider Education Project, led by the Ontario Thoracic Society and the Ontario Lung Association, workshops were delivered to small groups of health care providers across Ontario. The workshops included brief presentations on adult and pediatric asthma guidelines by local specialists using a standardized slide kit, followed by family practitioner-led case discussions.

A third APA initiative is the community-based Smoke-Free Homes and Asthma Project, led by the Program Training and Consultation Centre. Exposure to second-hand smoke is a known trigger factor for asthmatics, contributing to exacerbations that often result in emergency department visits and hospitalizations. Working through the local public health unit, community stakeholders support the dissemination of an information brochure in both English and French and window clings for homes and cars. The Northwestern Health Unit campaign used radio ads, community displays, “purple envelopes” containing the brochures, information sheets and window clings. The purple envelopes were advertised on the radio and distributed through schools, pharmacies, day care centres and libraries.⁶

Results of the KT experience

An objective evaluation is part of each initiative’s plan. Results are measured as changes in patient and/or provider practice, patient outcomes, patient and/or provider satisfaction and/or health care utilization. Initial evaluations are demonstrating statistically significant improvements in uptake and practice and will contribute to a broader provincial plan for asthma in Ontario.

A total of 351 health care providers (247 physicians and 104 allied health providers) attended workshops between September 2002 and March 2003. The workshops were very highly rated: 94% of participants

reported improved confidence in asthma management and 98% of participants indicated they would recommend them to a colleague. Self-reported practice changes three months after the workshops included altered prescribing patterns, educational interventions and use of written action plans.⁷

For the Smoke-Free Homes and Asthma project, an independent research company undertook a pre- and post-campaign telephone survey of randomly selected residents. Of 292 respondents who recalled the campaign, 23% reported talking to people about it afterwards and 12% reported restricting smoking after seeing, hearing or reading about it. Of 96 respondents who smoke and recalled the campaign, 30% reported changing their smoking habits after seeing, hearing or reading about smoke-free homes.

Lessons learned

- Multidisciplinary teamwork can be more efficient and lead to improved results. However, there is a learning curve as members come to appreciate varying perspectives and issues and recognize their roles should be complementary, rather than competitive. Conflicts can still arise. For example, clinicians' appreciation of the often-lengthy research process may still compete with their motivation to quickly implement an initiative.
- Agencies outside the health care system bring a non-medical perspective to client-centred initiatives and often identify gaps in the medical process. For example, the Farm Safety Association's input into asthma education information for agricultural and horticultural work settings identified triggers such as feather tips and fungal spores that were not previously considered as part of the asthma education approach.
- Community-based efforts support sustainable programs. Generic, evidence-based program standards can be molded by a community approach that takes local resources and processes into consideration, thus building local capacity to manage asthma.
- Partnerships beget new partnerships, which produce larger effects than any individual group could accomplish on its own. For example, the Windsor Essex County Community Asthma Care Strategy (ECCACS), funded by the Primary Health Care Transition Fund, partnered with a number of APA initiatives, which led to a joint initiative to support the Daimler-Chrysler Canada Inc./Canadian Auto Workers' award-winning "Working Toward Wellness" program. One of their healthy workplace initiatives for 2005 is the Asthma Wellness Program, planned in collaboration with ECCACS and APA agencies.

There is a learning curve as members come to appreciate varying perspectives and issues and recognize their roles should be complementary, rather than competitive.

Conclusions and implications

The development, implementation and evaluation of the APA initiatives support programs and practices that take local resources and the needs of the local patient population into account, with the aim of integrating best practice into medical care and home, work, school and social environments. With a strong focus on primary care and school/work settings, health promotion and early intervention efforts are intended to reduce health care utilization and improve patient outcomes.

Researchers from a number of the APA initiatives are working in collaboration with staff from other provinces to share their experiences. For example, University of Toronto researchers are working with researchers at the Alberta Asthma Centre in Edmonton on the implementation of two school-based asthma educational

initiatives. There is also interest from other provinces in the surveillance systems to be used as a key tool for monitoring performance indicators on an ongoing basis.

In the future, the APA initiatives will continue to be reviewed, revised and reassessed to ensure relevance. As well, ongoing guideline updates for front-line providers, patients and targeted audiences will continue to support translation of research knowledge to practice. Results of the pilot projects will contribute to the next phase of the Ontario asthma strategy.

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LESSONS FROM DISSEMINATION AND CAPACITY BUILDING IN THE CANADIAN HEART HEALTH INITIATIVE

Kerry Robinson, McMaster University
Dr. Susan Elliott, McMaster University
Dr. Jennifer O’Loughlin, McGill University
Dr. Roy Cameron, University of Waterloo
Dr. John Eyles, McMaster University
Dr. Dexter Harvey, University of Manitoba

The Canadian Heart Health Dissemination Project (CHHDP) brings together learnings from a long-running series of provincial projects designed to conduct research and interventions to inform cardiovascular disease prevention policies and practices. With a focus on the relationships between dissemination and capacity building, the CHHDP highlights opportunities to support health promotion efforts by considering both organizational and environmental factors. Effective capacity building and dissemination appear to require appropriately skilled and committed people, strong communication channels through extended networks, the commitment of both research and policy/practice groups and senior level buy-in.

Background

The Canadian Heart Health Dissemination Project (CHHDP) is a six-year, CIHR-funded project (2000-2006) focusing on a synthesis of learnings from the provincial dissemination projects that make up the Canadian Heart Health Initiative (CHHI). Over the past 15 years, the CHHI, under leadership from Health Canada, has brought together researchers and public health leaders in each province to conduct research and interventions to inform cardiovascular disease prevention policies and practices.

To reduce preventable deaths from chronic diseases, evidence-based approaches must be disseminated across public health systems. To succeed, we must also build capacity to disseminate practical and effective health promotion strategies. The primary goal of the CHHDP is to advance our understanding of dissemination research and capacity building in order to more effectively deliver heart health promotion in Canada.

The CHHDP focuses on the relationship between dissemination and capacity, drawing on knowledge from a range of provincial health system contexts, types of public health organizations and intervention approaches. Our key audiences include the Public Health Agency of Canada (PHAC), the Pan-Canadian Public Health Network, the Chronic Disease Prevention Alliance of Canada (CDPAC) and the Intersectoral Healthy Living Network, as well as provincial ministries of health and regional health organizations responsible for planning and implementing chronic disease prevention and healthy living activities.

The KT initiative

The CHHDP is guided by five objectives:

- to understand the concepts of capacity and dissemination;
- to measure current levels of chronic disease prevention capacity and dissemination;
- to explore effective interventions used to guide dissemination and how they have influenced capacity building;

- to examine contextual factors affecting dissemination interventions and research processes; and
- to identify the factors that support or impede these processes.

This synthesis research program required collaborative partnerships with researchers from the provincial dissemination projects, and has been built around linkage and exchange. We employed a combination of comparative case studies of provincial projects and a national cross-sectional survey. Both qualitative and quantitative data were collected: qualitative analysis of project reports, interviews and health policy documents, and quantitative data collection using a national survey of public health resource and program delivery organizations.^{1,2}

We were guided by strategic and research advisory groups made up of research and policy representatives from each province, as well as ongoing communication with CDPAC and PHAC. We built upon existing research/policy partnerships developed by each provincial heart health dissemination project at regional and provincial levels and existing relationships at the federal level (e.g. with Health Canada and the Heart and Stroke Foundation of Canada).

We have worked in partnership to refine our objectives, inform methods and tools, validate research findings and shape dissemination activities. We also contributed to capacity building and knowledge exchange through the sponsorship and organization of a supplemental journal issue collecting papers from each CHHI provincial project³ and sponsorship of provincial projects to present findings at national conferences. Ongoing linkage and exchange were facilitated by annual face-to-face advisory group meetings; regular e-mail communication focused on review and feedback; regular one-on-one telephone communication; electronic newsletters; ad hoc regional teleconferences; and a national project website housing project publications, presentations, and meeting minutes.

Results of the KT experience

On their own, information sharing and communication are insufficient to successfully support knowledge uptake among public health organizations.

Our results reveal that dissemination is understood as an active and planned series of steps reflecting a transfer process as well as an uptake or implementation process.* Capacity building—that is, efforts to enhance the ability of an organization to effectively plan, implement, evaluate and sustain health promotion efforts—was found to not only be a complementary and closely-related strategy to dissemination, but essential to ensuring uptake and use of research and practice innovations. On their own, information sharing and communication are insufficient to successfully support knowledge uptake among public health organizations.

Effective dissemination was found to be based on a knowledge exchange process between resource groups (research and intervention staff) and public health user groups, including active efforts to enhance will/commitment, knowledge, skills, leadership, resources, infrastructure and partnerships.

The most commonly used capacity building and dissemination strategies across the projects included communication activities (meetings, electronic media, teleconferences and newsletters);

* Findings presented here are based on six provincial projects studied to date (Ont., Man., P.E.I., Nfld., Sask., B.C.). The provincial projects were funded on a staggered basis; as such, Alberta analysis is ongoing through 2005.

collaboration/partnership development; resource provision (information and financial); workshops/training; networking (peer exchange); facilitation; and linking systems and individuals (to maintain communication between resource and user groups).

The most frequently identified characteristics of effective capacity building and dissemination centred on having a leader or champion within the public health user group; cultivating relationships and buy-in among user groups; providing adequate resources to support capacity building and dissemination; providing user groups with access to central resource staff for technical assistance; and tailoring interventions to the needs of user groups.

Our qualitative and secondary quantitative analysis revealed a number of areas of health promotion capacity and programming that showed growth during the six provincial projects. However, these projects and their interventions did not exist in a vacuum; other provincial health system changes, professional development opportunities and health promotion initiatives occurred concurrently and often in partnership with the provincial projects. Observed changes must be seen in this broader context.

Overall, there is not a consistent pattern across provincial projects in terms of evidence of effectiveness of their capacity building and dissemination interventions. For two provinces, British Columbia and Saskatchewan, there was documented growth in capacity elements in some regions and decreases in others. This is likely to be related to the destabilizing role of provincial health system reform, which affected project activities. However, in the other four provinces (Ontario, Manitoba, Prince Edward Island, and Newfoundland), a range of positive changes was documented in most, if not all, elements of both chronic disease prevention/healthy living capacity and implementation, including knowledge and skill development, partnerships, resource acquisition, organizational structure, level of program delivery, scope/type of programming and program sustainability.

The findings from all projects show that a common set of factors act as facilitators or barriers to both capacity building and dissemination:

- Appropriately skilled/committed people
- Funds/resources
- Priority/interest
- Leadership/champions
- Communication channels/processes
- Structure/internal coordination
- Partnerships

The main difference between factors influencing capacity building versus dissemination is that the presence or absence of partnerships appears to play a more prominent role in dissemination, while having leadership among public health user groups appears to be more important for capacity building. Finally, a number of broader provincial contextual factors were found to influence public health capacity and program implementation, such as provincial health system reform, geography and demographics, socioeconomic climate, political climate, provincial leadership and provincial culture.

Lessons learned

These findings highlight opportunities to support health promotion capacity building and dissemination by considering both organizational and provincial environmental factors. The recurring importance of having appropriately skilled and committed people suggests that ongoing professional development opportunities for

regional health staff and volunteers, along with having central provincial resource staff to provide facilitation, resources and technical support, are key. Moreover, provincial and regional health organizations must not only explicitly identify health promotion priorities, but they must also protect health promotion time and resources against competing issues or crises. Perhaps most important for creating such an environment is the need for research and practice organizations to foster health promotion champions that are able to support knowledge translation.

Sustainability is also important. Provincial departments and regional health organizations need to coordinate their priorities and work together to minimize disruptions to front-line practice during times of reform and system instability. Like health promotion practice itself, there is no single strategy or approach that works best for capacity building and dissemination. Rather, multiple strategies that can be tailored to public health user organization needs, and that target front-line staff, senior leadership and organizational cultures, are required.

Conclusions and implications

Based on both our research findings and the dissemination research literature, we developed a unified model of dissemination that can be used with a range of public health organizations and contexts. Three overriding themes were identified: a two-way interactive exchange process is most likely to succeed; dissemination involves multiple steps to facilitate transfer and uptake, including capacity building; and dissemination depends on key linking individuals from user and resource groups to facilitate communication and lead joint activities.

While there is no gold standard method for dissemination, it must be actively initiated and include the commitment of research and policy/practice groups, strong communication channels through joint groups or extended networks and senior level buy-in and appropriately skilled people dedicated to linking and facilitation roles.

The findings presented here provide part of the picture of healthy living and chronic disease prevention capacity building and dissemination in Canada. As the CHHDP draws to a close, it will further broaden our understanding of not only what works and under what conditions, but what the remaining policy/practice needs are in Canada as policy shifts towards chronic disease prevention and healthy living promotion. An ongoing step in this national synthesis work is knowledge exchange with decision-making audiences to facilitate translation of these learnings into public health policy and practice.

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THE CANADIAN AIDS TREATMENT INFORMATION EXCHANGE

Timothy Rogers, PhD, Canadian AIDS Treatment Information Exchange

The Canadian AIDS Treatment Information Exchange (CATIE) is a highly successful national HIV/AIDS treatment information service. Working in partnership with a network of other information providers, CATIE develops and disseminates plain-language, research-based treatment information; brings together people living with HIV/AIDS, researchers and health care providers to facilitate knowledge exchange; and conducts community-based research to inform research priorities and policy development. CATIE's success is due in part to its commitment to community-based development, mobilizing individuals and communities to respond to treatment issues, and connecting to regional initiatives.

Background

Since the beginning of the HIV/AIDS epidemic in the 1980s, the tremendous advancements in its management have been driven by fast-paced developments in clinical, epidemiological, social and basic science research. Throughout this time, knowledge translation (KT) has played a pivotal role in improving the health of affected individuals and communities.

The Canadian AIDS Treatment Information Exchange (CATIE)* grew out of the early community-based advocacy movement to improve HIV health policy and health care. At a time when the medical community had little to offer people living with HIV/AIDS, CATIE was one of the first organizations in Canada to systematically assemble and disseminate treatment information. For communities devastated by the epidemic, “the idea that information could save lives was revolutionary”.¹

Since the early 1990s, CATIE has expanded from a local, Toronto-based group to a national, bilingual treatment information service, largely through the support of Health Canada's national HIV/AIDS strategy. Our mission is to improve the health and quality of life of people living with HIV/AIDS in Canada by providing them, and the people and organizations that support them, with accessible, accurate, unbiased and timely treatment information. We work in partnership with a network of other information providers (including researchers, health care providers and peers) to ensure that people have access to the information they need, in the form they desire, to make informed health care choices.

The KT initiative

KT—bringing emerging research developments to people who can benefit from the knowledge, and helping to ensure the experiences of individuals and communities affected by HIV inform further research—is a core function for CATIE. Our key KT goals are to promote the empowerment of people living with HIV/AIDS and their caregivers to make informed health care decisions; build the KT capacity of the loosely-structured HIV/AIDS treatment information network throughout Canada; and serve the evolving HIV/AIDS treatment information needs of diverse communities in partnership with community organizations.

* For more information about CATIE, visit <http://www.catie.ca>.

Our KT activities include:

- Providing research-based information (including developments in clinical and population-based research) in meaningful, plain-language formats through multiple channels (print, electronic, telephone, website and workshops/forums).
- Developing partnerships with vulnerable communities to identify, research and address barriers to treatment and to knowledge building in health management.
- Bringing together communities of care (people living with HIV/AIDS, researchers, health care providers, caregivers) to facilitate knowledge exchange.
- Working in partnership to conduct community-based research and to inform research priorities and policy development.

Our evaluations have consistently shown that people want quality treatment information from trusted sources.^{1,2} Quality treatment information is accurate, timely, research-based, unbiased and comprehensive. For people living with HIV/AIDS, quality information is also accessible, meaningful and contextual.

We have a community health advisory committee composed of HIV researchers, physicians, nurses and community leaders who provide ongoing input on emerging research and clinical trends to which we should be responding. They worked with us to establish a research and information assessment strategy, which includes guidelines about reviewing, assessing and using different sources for treatment information (such as informed expertise, expert-reviewed literature and experiential information). They also help us identify leading physicians, pharmacists and other health care providers whom we use as expert reviewers, presenters and writers. In addition to information on conventional medicine, we provide research-based information on nutrition and complementary therapies and have worked closely with the Natural Health Products Directorate to promote KT in this sector. We have also established a partnership with the Canadian HIV Trials Network to provide information on clinical trials currently enrolling in Canada.

Results of the KT experience

CATIE's model has proven itself in many evaluation studies and through feedback with service users over the past 14 years. A 2002 evaluation found "the primary outcome of CATIE was accessible and trustworthy treatment information presented from a Canadian perspective and in a manner that empowered information users (both individuals and organizations)".² It also found that the evolution of CATIE to a national organization has had an important impact on the overall network of HIV treatment information providers.

HIV disproportionately affects vulnerable populations already marginalized from the health care system. We have found that community-based development plays an important role in bringing successful KT to these groups. We have worked with AIDS service organizations providing services to specific ethnocultural groups to support the creation of culturally sensitive, multilingual treatment information. Through a partnership among a children's hospital, a youth-based AIDS service organization, community-based researchers and others, we have investigated the needs of HIV-positive youth and are currently developing a youth-oriented website for HIV treatment information. In another collaborative research project involving universities, rural AIDS service organizations and local public health workers, we are looking at treatment information networks in rural communities and how best to address barriers to KT.

Lessons learned

The expansion to a national service-based organization was very difficult for CATIE. Our challenge was to maintain strong community-based roots while addressing the daunting diversity of regional needs and issues. We first tried a governance structure with a local board of directors and a national advisory committee. However, this did not allow for adequate regional engagement and we moved to a fully national board.

As a national organization, CATIE was originally envisioned as a service directly to end users of the information, most importantly people living with HIV/AIDS. But creating awareness of such a service was a significant challenge with our limited funding. Moreover, an environmental scan showed that many people living with HIV/AIDS preferred to get their treatment information from local sources with whom they had an existing relationship. The availability and quality of such information also varied enormously throughout the country.³ This led us to develop stronger partnerships with local community-based organizations and to assume a leadership role in building the capacity of existing networks to manage, exchange and disseminate treatment information.

We have had to adapt our KT strategies to the constantly changing HIV/AIDS environment—from communication technologies, to audiences, to the pace of research developments. While we originally focused on a 1-800 phone line and printed publications to reach a pan-Canadian audience, our website has since grown into our most important vehicle for information dissemination, with more than 10,000 pages of content and more than 650,000 visits per year.

In the beginning, our information was targeted to an educated, middle-class, gay population that was thirsty for information. However, as the epidemic spread to other marginalized populations, we have had to grapple with issues such as ethnocultural diversity, gender-specific needs, harm reduction, co-infections and low health literacy.

We have also adapted our services through a changing landscape of research and knowledge building. In the early days, there were no drug treatments for HIV. The focus was on preventing and treating AIDS-related infections/conditions and treatment information went hand-in-hand with advocacy. In the mid-1990s, antiretroviral treatments started to show promise in clinical trials and an explosion of treatment information began—suddenly, clinical practice could change monthly as new research developments were reported. More recently, the KT environment is probably best characterized as “treatment information overload” and a major challenge is to help people sort through the massive amounts of research information available.

Conclusions and implications

In a review of CATIE’s program and service evaluations completed over the past few years, we identified the following elements as crucial to our success, and hope they can inform KT activities in other areas of population and public health.⁴

More recently, the KT environment is probably best characterized as “treatment information overload” and a major challenge is to help people sort through the massive amounts of research information available.

Community-based action

We mobilize individuals and communities to respond to HIV/AIDS treatment issues by working in partnerships and connecting to regional initiatives. We have found that a capacity development approach is most successful, which includes supporting leadership, organizational development and community organizing around KT. The ongoing involvement of people living with HIV/AIDS and their communities is essential.

Quality information

We develop products and services that are both research based and relevant to community needs. The creation of quality information involves engaging all stakeholders in the KT process—researchers, clinicians, community leaders and people living with HIV/AIDS.

The creation of quality information involves engaging all stakeholders in the KT process—researchers, clinicians, community leaders and people living with HIV/AIDS.

Accessibility

We ensure that our products and services are right for our target audiences. We provide treatment information through multiple channels, targeting diverse audiences with information that “speaks to them”, providing context for treatment information and being a responsive community presence.

Promoting empowerment through information

Drawing from learner-centred principles of adult education, we work to support people living with HIV/AIDS and their caregivers to develop their capacities for researching, assessing, understanding and making use of treatment information. Through this, we help people make informed decisions, build successful health care relationships and act on the health issues that are important to them.

Considering all determinants of health

Health is determined by complex interactions among social and economic factors, the physical environment, and individual behaviour. As a result, we work from a broad concept of treatment, and attempt to impact both social factors and individual health behaviours.

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