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KNOWLEDGE TO ACTION: AN END-OF-GRANT KNOWLEDGE TRANSLATION CASEBOOK



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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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FOREWORD

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New knowledge emerging from research holds great potential to expand horizons and create significant impact. Knowledge translation (KT) is about harnessing that potential and bridging the gap between what we know and what we do.

The Canadian Institutes of Health Research (CIHR) views KT as an essential component in improving the health of Canadians and has made it one of the cornerstones of its mandate. It is by moving research into action that the true benefits of our investment in health research can be realized.

CIHR has identified two broad categories of knowledge translation. The first, **integrated KT**, is an effective way of doing research that involves collaboration between researchers and knowledge users at every stage of the research process – from shaping the research question, to interpreting the results, to disseminating the research findings into practice. This co-production of research increases the likelihood that the results of a project will be relevant to end-users, thereby improving the possibility of uptake and application.

The compilation of case studies found in this publication concerns itself with the second and equally important category of knowledge translation, end-of-grant KT. **End-of-grant KT** refers to the dissemination of findings generated from research once a project is completed, depending on the extent to which there are mature findings appropriate for dissemination. Researchers who undertake traditional dissemination activities such as publishing in peer-reviewed journals and presenting their research at conferences and workshops are engaging in end-of-grant knowledge translation.

The concept of end-of-grant KT incorporates a continuum of activities that can vary in their level of intensity. At one end of the intensity spectrum, *diffusion (let it happen)* involves a generalized approach to sharing research findings with a broad audience. Almost all of the projects in this casebook undertake diffusion as part of their KT activities, sharing the results of their research in academic journals and at conferences.

Dissemination (help it happen) refers to a more targeted and tailored approach to sharing research evidence with knowledge users. This often includes activities such as developing summaries for stakeholders, educational sessions for knowledge users, engaging knowledge users in developing dissemination activities, creating tools and engaging the media. You will find that the majority of the cases in this publication have tailored their KT activities to the appropriate knowledge-user audiences, resulting in more effective uptake.

Application (make it happen) moves beyond awareness and actively attempts to engage knowledge users to adapt and adopt the research evidence – assuming there is a strong evidence base – to a practice or policy setting. It is often a fundamental component of integrated KT. Activities that fall into the scope of application include identifying barriers to the uptake of research findings, adapting knowledge, tailoring messages and interventions to overcome the identified barriers, evaluating the implementation process

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and outcomes, and finally, sustaining knowledge use. Several of the projects featured in this casebook produced research findings where it was appropriate within the context of the knowledge user environment to actively apply the evidence.

The activities highlighted in this publication represent a diversity of end-of-grant KT strategies and cover a broad spectrum of research, from genetic research to population health interventions. The common element driving successful knowledge translation in each of the case studies reported here is the development of a well-defined plan that successfully guides the research team in its end-of-grant KT activities. CIHR has created a guide to support researchers and knowledge users in developing strong end-of-grant KT plans. This guide, along with a guide on integrated KT, is available on the CIHR website (www.cihr-irsc.gc/ca/e/38766.html).

Emerging from these cases are five key components of a strong end-of-grant KT plan:

- *Goals*

KT goals need to be clearly defined and justified, whether it is to raise awareness or promote action. These goals may be modest or ambitious; however, they must be appropriate to the nature of the research findings and the target audience. Nadine Wathen and her colleagues (Case study 8) made it their goal to better inform decision makers working in family violence by sharing the synthesized findings from several research projects. On the other hand, Kate Shannon's team (Case study 5) felt it was important to more actively apply their research evidence to health policies and practices geared towards street-based sex workers.

- *Audience*

It is important to identify and justify the target audience for end-of-grant KT activities. All of the cases in this book clearly demonstrate a detailed understanding of their knowledge-user audience and the extent of their decision-making role with respect to the research findings. Geoffrey Fong and his team (Case study 9) understood that in order to improve tobacco control policies, their KT activities had to reflect the state of their audience's current knowledge, how they tend to use knowledge and the formats in which they prefer to receive their information. Similarly, ensuring that the mining industry, health care providers and municipal government representatives were all at the table was essential to the successful dissemination of research produced by Janis Shandro's team (Case study 6).

- *Strategies*

KT strategies or interventions support the KT goal and adapt the knowledge to the identified audience's needs and context of use. The nature of the target audience and the type of evidence will determine which strategies – diffusion, dissemination and application – are appropriate. For example, Diane Russell's team (Case study 4) decided to use teleconferenced meetings given the hectic schedules of their target audience. Mira Johri (Case study 3) evaluated the barriers and facilitators to uptake of her research on mother-to-child transmission of HIV and recognized that targeted decision makers would overlook their prior reservations about the value of plain language summaries once they realized how helpful they could be in contributing to Guatemala's national HIV strategy.

- *Expertise*

The specific KT goals, audiences and strategies planned for determine the appropriate level of expertise needed for end-of-grant KT. Katherine Boydell (Case study 2) required the involvement of a choreographer to implement her innovative approach to sharing evidence. The Allergen Consortium (Case study 7) relied on expertise in bioinformatics to ensure that its target audience could search and sort through reams of genetic data.

- *Resources*

End-of-grant KT can only be successful if the appropriate resources are dedicated to accomplish proposed activities. The NutriSTEP® team (Case study 1) quickly realized the value of having web content experts assist with the development of a website and secured additional resources to make this happen.

For all KT activities, the most important overarching consideration is *appropriateness*. Each discipline, research project and knowledge-user community is different. A single study can represent the culmination of a large body of work ready for application, or a nascent area of research where the findings might be the product of chance or bias, in which case KT efforts to apply the findings could result in more harm than good. The key to success is judicious KT that takes into account the strength and transferability of research findings, the target audiences, the means of transmission and the context for application.

CIHR is unique in that its mandate requires it not only to create new knowledge, but to translate that new knowledge into benefits for Canadians and individuals around the world. The researchers you will read about in this publication have taken advantage of CIHR's KT Supplement grants and have adopted unique and effective ways in which to translate their research into action. On behalf of CIHR, I thank them for their work.



Dr. Ian Graham
Vice-President, Knowledge Translation and Public Outreach
Canadian Institutes of Health Research

1. BRINGING NUTRISTEP® TO THE WORLD WIDE WEB

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Janis Randall Simpson, University of Guelph

Heather Keller, University of Guelph

Joanne Beyers, Sudbury & District Health Unit

Lee Rysdale, Nutrition Resource Centre, Ontario Public Health Association

*NutriSTEP® Online © 2009 Sudbury & District Health Unit, Janis Randall Simpson,
Heather Keller and the Nutrition Resource Centre*

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Background

Childhood nutrition directly affects growth and development. In the long term, nutrition also influences the occurrence of chronic diseases such as diabetes, heart disease and obesity. This is what makes identifying nutrition risk in preschoolers so important.

Joanne Beyers, Heather Keller, Janis Randall Simpson and Lee Rysdale created NutriSTEP® (Nutrition Screening Tool for Every Preschooler) to serve this purpose, as there was previously no equivalent method for childhood nutrition screening. NutriSTEP® is a community-based, parent administered, nutrition risk screening questionnaire.¹ Its development, over ten years, involved almost 2000 ethnically and culturally diverse preschoolers and their parents, and more than 50 multisectoral partners across Canada. It was scientifically validated through a CIHR-funded project, *Nutritional risk in Canadian preschoolers: Prevalence and models*. Since the validation of NutriSTEP®, the research team has conducted further research on models for screening nutrition risk among preschoolers. Using NutriSTEP® for preschool nutrition risk screening has been demonstrated to be not only feasible but sustainable.

The NutriSTEP® program includes not only a screening questionnaire, but an Implementation Toolkit, related educational resources and training materials. The NutriSTEP® Implementation Toolkit contains information on how to plan and implement a preschool nutrition screening program. Such a program could have a large variety of applications, including early intervention initiatives, community child health program planning and evaluation, and population health surveillance. The research team has received many requests from across Canada and other countries about the program; hence, there is a demonstrated need for widespread dissemination of information.

KT Goal

Disseminate to a widespread audience an evidence-based, sustainable tool to support nutrition risk screening among preschoolers.

Knowledge Translation Strategy

Canadian research² has shown that the Internet is an effective means of disseminating information to public health practitioners, and a cost-effective and valuable collaborative tool for knowledge translation (KT).

Audience

- Registered dietitians
- Public health units
- Other health professionals
- Parents
- General public

Accordingly, the team developed a website for the NutriSTEP® program.³ The website is designed to post documents tailored to different audiences, such as health professionals and the general public. It also includes background information, FAQs (frequently asked questions), an online community, information on research activities and support materials such as the Implementation Toolkit, educational and training resources, as well as documents in French.

Since registered dietitians (RD) are key stakeholders in nutrition risk screening, a link to the NutriSTEP® website is displayed on the Dietitians of Canada (DC) website and on Healthy Start for Life, a mini website within the DC's website specifically designed for parents and caregivers of preschoolers.

Team members undertook a number of complementary KT initiatives as part of the NutriSTEP® program. They observed, albeit anecdotally, many gaps in parents' nutrition knowledge throughout the development and refinement phases of NutriSTEP®. For example, a lack of knowledge about growth, appropriate portion sizes for preschoolers, developmental milestones, and children's food and eating habits.⁴ Consequently, they developed a 12-page document, *ABC's of Feeding Preschoolers – NutriSTEP® Guide*, in English and French, which received an award from Dietitians of Canada in 2003. They also developed and evaluated⁴ a four-page condensed NutriSTEP® educational booklet, *How to Build a Healthy Preschooler*. They recently

updated it and made it available through the Nutrition Resource Centre in Ontario.⁵ The booklet has also been culturally adapted and translated into Vietnamese, Punjabi, and simplified and traditional Chinese. Since June 2009, print copies of the NutriSTEP® questionnaire and of *How to Build a Healthy Preschooler* are available free of charge for public health units in Ontario. To date, over 100,000 copies have been distributed.

KT Strategies

- Disseminate resources to target audiences through the development of an effective website.
- Create tailored toolkits and learning modules targeted to health professionals.
- Develop a plain language, culturally adapted and translated nutrition guide for parents from ethnically diverse communities.

The team also developed five self-directed training modules, or Nutrition Primers, for service providers, and particularly RDs, who receive high nutrition risk referrals. These modules are available in English and French on the NutriSTEP® website.

Traditional research dissemination methods, such as the publication of journal articles and conference presentations, have their limitations since many end users of research have not been sufficiently involved in research and KT activities. The team was well aware of this and has sought opportunities to interact directly with intended end users throughout the project. These included invited presentations, networking groups at the local, regional and national levels, and the involvement of key stakeholders in the development of NutriSTEP®.

Impact

The NutriSTEP® questionnaire is protected by copyright and distribution rights have been assigned to the University of Guelph Business Development Office. Since July 2008, licences for the NutriSTEP® questionnaire, in English and French, and for the Implementation Toolkit are available on www.flintbox.com, an online portal for university technologies. At the end of 2009, more than 150 licences had been granted for the questionnaire.

Since the website was launched in late June 2009, it received over 7500 visits, indicating very strong interest in the program. The most popular pages are those describing the Implementation Toolkit, general information about the NutriSTEP® program, information on how to obtain a NutriSTEP® licence, and the FAQs. In the first six months, 400 Implementation Toolkits and 70 Primers for RDs were downloaded. In addition, 20 individuals have signed on as members of the NutriSTEP® Online Community, which supports community professionals in the implementation of NutriSTEP® screening and serves as a forum where users and site coordinators share their experiences and resources. Community professionals who work with children and are interested in conducting nutrition screening can also join to find out more about NutriSTEP®.

A number of implementation success stories are highlighted on the website, including:

Alberta Health Services piloted the implementation of NutriSTEP® in urban and rural Community Health Centres, in conjunction with preschool immunization. A link was created with the Pediatric Dietitian Service at urban locations for the referral of high-risk children. NutriSTEP® made a valuable contribution for a complete nutrition and growth assessment.

The Thunder Bay District Health Unit launched NutriSTEP® in 2008 through their Fair Start program, a community partnership for screening children aged 18 months to four years. In 2009, the NutriSTEP® questionnaire was added to the junior kindergarten screening booklet that Fair Start distributes to all children registered for kindergarten in the city and district. Learning Centre teachers, facilitators and certified Fair Start screeners have been trained to administer the NutriSTEP® questionnaire and make referrals. Similar training was provided to public health nurses and home visitors through the Healthy Babies Healthy Children program this winter.

New Brunswick Public Health plans to introduce NutriSTEP® at their preschool screening clinic for 3½ year olds under its Early Childhood Initiatives program. This will provide an

Impact

- *A number of regional health service providers have integrated NutriSTEP® into their preschool screening activities, with very positive results.*
- *Since dissemination efforts began, over 150 licences have been granted for the NutriSTEP® questionnaire.*



NutriSTEP®

**Nutrition Screening Tool
for Every Preschooler**

**Évaluation de l'alimentation
des enfants d'âge préscolaire**

opportunity to discuss children's growth and developmental milestones with a public health nurse and gather information. New Brunswick Public Health officials participated in early phases of the development of NutriSTEP® and are very excited to introduce a valid and reliable bilingual nutrition screening tool for the preschool population.

Other implementation success stories will be added to the website in early 2010.

Lessons Learned

The research team played a major role in developing the website in collaboration with the Nutrition Resource Centre. Initially, the intention had been to draft the text for the website. However, team members soon

discovered that they did not have the skills to handle all aspects of this work. It was thus necessary to hire experienced professionals on contract, which required additional funds. The website development was also a very time-consuming process. Nevertheless, the project was successfully completed. If they had to do this again, they would increase their budget to allow for more expert help in the design and development of websites.

Expertise and Resources

Website development posed more of a challenge and required more resources than was initially anticipated.

Next Steps

The next steps for the NutriSTEP® program include a number of projects designed to increase the accessibility of the questionnaire. Team members are currently testing the reliability of an electronic version compared to the current paper version. They also plan to translate NutriSTEP® into traditional and simplified Chinese, Vietnamese and Punjabi to accompany the culturally adapted and translated educational booklet already available in these four languages. Finally, they received a CIHR grant to develop a Toddler NutriSTEP® in response to requests from the field to offer valid and reliable nutrition risk screening for children younger than preschoolers.

Notes

- ¹ Randall Simpson J.A., H.H. Keller, L.A. Rysdale and J.E. Beyers (2008). Nutrition Screening Tool for Every Preschooler (NutriSTEP™): Validation and test-retest reliability of a parent-administered questionnaire assessing nutrition risk of preschoolers. *Eur J Clin Nutr.* 62:770-780.
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- ³ www.nutristep.ca
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- ⁵ www.nutritionrc.ca

2. RESEARCH-BASED DANCE AS A KNOWLEDGE TRANSLATION STRATEGY

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Katherine Boydell, Senior Scientist, Hospital for Sick Children (Toronto)

Siona Jackson, Choreographer, Creative Habitat for Social Change (Toronto)



Photo by Ashley Hutchison

Background

In a CIHR-funded study, *Youth Experiencing First Episode Psychosis: A Comprehensive Examination of Pathways to Care*, a series of case studies were used to try to understand why young people experiencing a first episode of psychosis delay seeking help. Findings revealed the dynamic complexity and inter-relatedness of the roles of family, school, community, treatment system and illness experience in the pathway to mental health care. Although each individual pathway was unique, some common elements included difficulty on the part of general practitioners to detect psychosis; the impact of substance misuse; the dearth of involvement by schools; and feelings of isolation and paranoia preventing youth from telling others and seeking help. The problem of stigma was also identified as a critical factor in the delay. There is a pervasive need for knowledge regarding psychosis and the inability of schools and peers to identify psychosis, which results in a longer delay before seeking treatment. Research participants acknowledged that they might have sought help earlier if they had known their symptoms may have been related to early signs of psychosis.

KT Goal

Educate target audiences by taking an unconventional and provocative approach to disseminating research evidence.

Youth, family members, service providers and the general public must be educated about the early signs of psychosis. Not enough people are aware that this illness is treatable and that recovery is expected, particularly when identified early. Despite efforts to increase awareness about first-episode psychosis and mental illness in general, strategies to educate young people, their families and the wider community have been largely

Audience

- Youth
- Family members
- Health service providers
- Educators
- Academics
- Policy makers
- Artists

unsuccessful. The stigma and discrimination associated with mental illness prevent young people from seeking help and generate derogatory, stereotyped reactions from society. This problem calls for creative, innovative and provocative strategies.

Knowledge Translation Strategy

A research scientist and a dance choreographer partnered to co-create a 12-minute choreographed research-based dance performance^{1,2} to highlight the anguish of experiencing first-episode psychosis and the difficulties associated with seeking help. They used arts-informed methodology to

contribute to the understanding of pathways to mental health care, and also to explore the arts as an effective knowledge translation (KT) vehicle for communicating qualitative research and engaging with – and informing – multiple audiences.

Arts-based research provides a platform from which to begin a dialogue with young people, families and the public, to move them toward new ways of understanding and knowing. In representing the experiences of mental illness in a new evocative, illuminating and memorable way, viewers are challenged to engage with the

work and consider the cultural stereotypes that surround those with mental illness. The evocative representation of textual research results through dance can communicate moods as well as facts, which has the advantage of allowing the audience to engage in the phenomena in a deeper, more sensitive, open and meaningful way.

KT Strategies

- *Develop a research-based dance performance to communicate the experience of first episode psychosis and potential barriers to treatment.*
- *Evaluate audience engagement by analysing participant feedback.*

The theoretical underpinnings of the project draw from embodied inquiry.³ Embodied research is based on the traditional phenomenological notions of the “lived body” and the “lived experience”, which suggest that knowledge

has to do with lived experiences. Embodiment is conceptualized as an insightful and multidimensional means of linking body, movement and force as embodied rhythms, of how it is possible to be present, to live and experience, and to express and understand individuals from varied perspectives in nuanced contexts. Embodied inquiry attends to the relationship between language and the experiencing body, and has the capability of bringing the lived experience of individuals to the forefront. Todres (2007) states:

Words are not just tools or skills that are performed; they are experienced for how they feel; how they feel – the inner dimension of language – is an aesthetic quality central to the process of understanding; locates ourselves in relation to others – both personal and interpersonal; feeling is a form of understanding.

Impact

To date, the research-based dance has been performed live to academic, service provider, student, educator, artist, and policy-maker audiences. It has also been presented on DVD at numerous national

and international scientific conferences. The work has received media interest and was featured at the International Early Psychosis Association Film Festival in Melbourne, Australia,⁴ in a *Toronto Star* article⁵ and in an article published in the *Canadian Medical Association Journal*.⁶

Over 1,000 people attended the live performances. The methods used to assess audience engagement and elicit dialogue included in-theatre observation of audience responses, moderated post-performance large audience discussions, audience feedback in the form of ‘post-it’ notes, and researcher field notes. Analysis of this data suggests that dance is an effective way to share empirical research findings and to enhance awareness and understanding. It also highlights the importance of the aesthetic qualities and visceral impact of the performance.

Impact

Project results have spurred further research to explore the effectiveness of arts-based methods as a KT strategy.

The following are some examples of audience feedback received on ‘post-it’ notes:

...this reminds me why I do my job. Reminds me HOW I should ~ That words aren't enough to understand.

This was such a great public display of subjective experiences through an art medium. I believe this to be a powerful method to educate and sensitize about psychosis, but especially to fight against stigma!

Extremely interesting way of conveying the findings of the study. Provides a human face to this illness and the use of words, music, sound and dance is powerful. Evokes emotional response to subject matter.

A beautiful, moving and highly evocative communication of the lived experience of youth and their stories of psychosis. I was brought to tears. A wonderfully innovative way to share and communicate knowledge.

Next Steps

Pilot data from this research-based dance project have resulted in additional funding from CIHR and SSHRC to systematically study and evaluate the use of arts-based methods as a KT strategy in secondary schools. The school has been posited as the best place to increase mental health literacy⁷ and decrease stigma. The evocative representation of textual research results through the arts has the advantage of allowing the audience to engage in the phenomenon in a deeper, more sensitive, open and meaningful way. The research team will further explore the impact of using the arts to disseminate research on early psychosis and its impact on mental health literacy and stigma reduction. This work has also been instrumental in the development of an international arts-based health research collaborative.

Notes

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- ⁵ Funston, M. (2008). The people behind the breakthroughs. *The Toronto Star* (March 20th).
- ⁶ Fraser, J.L. (2008). Lifeworks: Dancing with research. *Canadian Medical Association Journal*. 179(5):450-451.
- ⁷ Mental health literacy has been defined as 'knowledge and beliefs about mental disorders which aid their recognition, management, or prevention' (Jorm, 2000).

3. PREVENTION OF MOTHER-TO-CHILD TRANSMISSION OF HIV IN GUATEMALA

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Mira Johri, University of Montreal

Background

In 2005, Guatemala received funds from the Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria (GFATM) for its HIV/AIDS strategy. As one of the four pillars of this strategy, Guatemala proposed to establish a new national program to prevent mother-to-child transmission (pMTCT) of HIV.

With funding from CIHR and other sources, Mira Johri and her research team designed, implemented and evaluated pilot HIV pMTCT programs in prenatal and delivery room care at the Hospital San Juan de Dios, one of Guatemala's two national hospitals. Their goal was to contribute to Guatemala's national HIV strategy by conducting operational research to inform evidence-based policy choices. They also sought to derive policy lessons relevant to other similar settings.

KT Goal

Reduce the rate of mother-to-child HIV transmission and improve women's health by disseminating critical research results to key decision makers to inform evidence-based policy choices.

The following insights needed to be transferred to policy makers and other stakeholders:

1. *Clinical success of the pMTCT pilot projects* – Clinical results for the pMTCT program were on par with best practices worldwide. The program reduced HIV transmission from mother to child from an estimated 30% without any intervention to less than 2%. Interventions to prevent MTCT and to treat maternal HIV were well accepted by patients.
2. *Intimate partner violence (IPV)* – Gender-based violence and gender inequality have a direct impact on the quality of life of women and children. They are determinants of a variety of health conditions, including women's HIV risk and poor birth outcomes. In their patient sample, the researchers found that verbal, physical and sexual violence by intimate partners in the last 12 months was common. Many key risk factors for IPV were also risk factors for HIV. Childhood sexual abuse was a strong predictor of IPV in adulthood, and IPV was linked to an increased risk of miscarriage.
3. *Risk factors for HIV in pregnant women: lessons for HIV prevention* – The study described risk factors for HIV infection in a sample of pregnant Guatemalans. Women in the sample exhibited few behavioural risks for HIV but significant vulnerability via partner behaviours. To stem feminisation of the epidemic, it was recommended that health authorities complement existing prevention interventions in high-risk populations with directed efforts towards bridging groups such as migrant workers. They identified four locally adapted HIV prevention strategies.

Audience

- *Policy makers*
- *Non governmental organizations (NGOs)*
- *Clinicians*
- *Activists*
- *Journalists*
- *Patients*
- *Professionals working in maternal and child health*

The project saved ten children from HIV, got 23 mothers on HIV treatment and gave more than 4500 women HIV counselling and testing.

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It also offered 2500 women nutritional screening and counselling, and gave about 750 women counselling on domestic abuse. Furthermore, it helped a leading hospital consolidate its abilities to perform HIV pMTCT and to strengthen its research capacity.

These results were unique and tremendously important in the Guatemalan context, where there was no established national pMTCT program, no routine HIV surveillance for the general population and very few services for IPV. It was important to communicate these results to stakeholders since research requires uptake to be useful.

Knowledge Translation Strategy

The focal end-of-grant knowledge translation (KT) activity was a dinner event where the study results were presented to approximately 120 national stakeholders, including key decision makers, representatives of NGOs, clinicians, activists, journalists, patients and other key individuals involved in the areas of HIV, IPV and maternal and child health. At the dinner, the Guatemalan research team made a presentation on

the study results, which was accompanied by a plain language brochure in English and Spanish. This activity was followed by discussions with key individuals in government and NGOs and impromptu presentations to groups of medical residents and clinicians.

The team's KT strategy reflects what John Lavis and colleagues at the Institute for Work & Health describe as "research exchange". The research exchange model promotes the establishment and nurturing of relationships amongst those who produce research and those who might use research knowledge. The aim is to bring about a cultural shift that facilitates greater use of research by decision makers and greater relevance in research orientations.¹ Accordingly, the team actively involved researchers and receptor communities in the formulation and conduct of research from

the start, and it ensured their ongoing participation in the project. This included consultations to help define research objectives and the inclusion of stakeholders as team members. This close collaboration promoted a feeling of shared ownership and a greater desire to learn about the project results. The dissemination strategy sought to emphasize face-to-face communication whenever possible as the most efficient way to transfer research² and to enhance its relevance, credibility and uptake.³

Impact

Although the research team had no formal evaluation process for the event, Guatemalan colleagues and collaborators commented uniformly that the study

KT Strategies

- *Increase the relevance of research results by taking an integrated KT approach involving knowledge users at an early stage of the project.*
- *Organize a dinner event to present research findings to a targeted audience.*
- *Supplement the presentation with a plain-language brochure outlining the research evidence and follow-up discussions with key stakeholders.*



Photo by Jesse Kao

was unique in attempting to return results to stakeholders, and they appreciated this tremendously. The KT initiative enabled them to highlight the excellent work of their Guatemalan colleagues on a national stage, to invest in their development as researchers by helping them to observe the entire process of knowledge production and translation, and to bring the benefits of what was learned to stakeholders in Guatemala. For these reasons, the research team feels that KT is essential to the ethical conduct of research in a developing country.

Lessons Learned

KT is particularly challenging for North-South scientific collaborations due to differences in social, organizational and professional cultures, incentives, opportunities and power structures.⁴ Political realities differ in Guatemala and Canada. Inclusion of government stakeholders as researchers or team members was a foreign idea to clinical colleagues in Guatemala, and considered by many to risk compromising research integrity and neutrality. Many felt that the Guatemalan government had historically not lived up to its mandate to protect, preserve and promote the health of its citizens, and doubted the sincerity of government representatives. They also questioned whether they had relevant competence to offer to a scientific project. This was an ongoing point of negotiation.

Lessons Learned

The research team overcame challenges posed by existing attitudes that undervalue key KT strategies like collaborating with end users and disseminating plain language summaries.

By being innovative, this project also raised a great deal of fear and anxiety among the Guatemalan research team. In a community where relatively few have training in epidemiology and biostatistics, technical language holds a great mystique. A plain language summary was considered “unscientific”. At least initially, many Guatemalan colleagues would have preferred a highly technical brochure that few could understand. They feared that they would be made to look foolish – and on a national scale! Their concerns were alleviated when the presentation and brochure were well received by the audience, and when the principal investigator answered technical questions competently.

Ensuring that research findings influence policy decisions is a continuous process. Not everyone was able to attend the KT event, and interest snowballed afterwards. In retrospect, it would have been useful to program two additional weeks of unscheduled time in the country to speak informally with all the relevant individuals.

Next Steps

The dinner offered the researchers an opportunity to work together to define the next phase of their project, which aims to guide decision making toward improving HIV pMTCT coverage nationwide while strengthening reproductive and child health services. This work recently received funding from CIHR. In collaboration with the World Health Organization, the team will seek to evaluate a range of priority maternal, neonatal and child health care interventions in Guatemala, including HIV pMTCT, at current and target levels of effective coverage. Equity issues will be given explicit consideration.

The team will launch a new, targeted KT effort when its first article designed to guide national HIV prevention policy will be published. Another article addressing various themes of domestic violence is underway. The team hopes that these articles will play an important role in informing policy debates.

Notes

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4. KNOWLEDGE BROKERING IN PEDIATRIC REHABILITATION: PUTTING RESEARCH RESULTS INTO ACTION

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*Dianne Russell, PhD,¹ Lisa Rivard, MSc,¹
Peter Rosenbaum, MD,¹ Steven Hanna, PhD,¹ Lori Roxborough, MSc,²
Dianne Cameron, MRSc,³ Doreen Bartlett, PhD,^{1,4} Johanna Darragh, PhD,⁵
Jan Willem Gorter, MD,¹ Stephen Walter, PhD,¹ Rachel Teplicky, MSc¹*

¹ CanChild Centre for Childhood Disability Research, McMaster University

² University of British Columbia

³ BC Centre for Ability (Vancouver)

⁴ University of Western Ontario

⁵ University of Alberta



Background

Physiotherapists (PTs) who treat children with physical disabilities such as cerebral palsy (CP) are challenged to find, understand and use information that is evidence-based. Outcome measures are an essential part of good evidence-based practice, but PTs are not always confident to select, administer and interpret available tests. Their measurement practices are not always supported by research evidence.

KT Goal

Improve evidence-informed practice within children's rehabilitation organizations by demonstrating the effectiveness and impact of an embedded knowledge broker.

Knowledge brokering (KB) is an approach to knowledge translation (KT) that supports evidence-based decision making in the organization, management and delivery of health services.¹ Evaluation of the effectiveness and impact of a KB role is not well established.

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As part of a CIHR-funded study, 25 PTs were engaged as knowledge brokers (KBs) in 28 children’s rehabilitation organizations, across three provinces, for an average of two hours per week for a period of six months. The research team facilitated the uptake of a suite of evidence-based measures by 122 PTs working with children having CP.

The researchers showed clearly that by providing modest financial remuneration, ongoing resource materials, and personal and intranet support, embedding a knowledge broker within each clinical site was effective in increasing the knowledge and use of specific evidence-based measures. The changes were sustained at 12 months. Interview data from KBs, administrators and participating PTs provided an understanding of the perceived usefulness of the role of KBs and the resources necessary to support the brokering process over the long term.

The researchers believe that their study makes an important contribution to the emerging body of literature on the effectiveness of using a knowledge broker as a KT strategy. They disseminated their results to the professional and scientific community through conference presentations and workshops, and several peer-reviewed publications are in progress. However, these more traditional strategies often do not reach clinicians and key decision makers at the level of the organization. For this reason, the researchers have sought to widen their KT strategies to more effectively reach these potential knowledge users.

Knowledge Translation Strategy

It is important for researchers and decision makers to continue to interact after research findings are released in order to facilitate the interpretation of the findings and determine how they can best be put into action.

The primary targets for the researchers’ end-of-grant knowledge translation activities were the individuals

from children’s rehabilitation organizations who participated in their study. They emphasized the involvement of administrators in this strategy because they have the authority to implement system-level changes.

Although a face-to-face meeting would have been the ideal strategy for facilitating continued interaction between the research team and the study participants, busy administrators and clinicians indicated that teleconference meetings might allow more participants to be involved. The

researchers thus organized a series of teleconferences, inviting all of the participants from the original study, including administrators, KBs and PTs. Separate teleconferences were held for each province to facilitate discussion of opportunities and barriers that might be specific to their geographical location. The focus of the teleconferences was to encourage participating sites to discuss the impact of the KB study, and whether and how participants might consider implementing a KB role more broadly. Multi-site participation in each teleconference promoted the exchange of ideas and encouraged potential future collaboration.

Prior to the teleconferences, the researchers produced a user-friendly report describing the main study, the results and the implications of the findings. They sent a draft of the report to KBs for feedback and made revisions based on their input. They then circulated the report to administrators, KBs and participating

Audience
Key knowledge users in children’s rehabilitation organizations, including:

- Senior administrators
- Physiotherapists
- Knowledge brokers

PTs at each of the 28 children’s rehabilitation organizations, along with an invitation to attend one of the teleconferences. The study report is currently available and can be downloaded from the *CanChild* website.²

The researchers developed two additional documents for teleconference participants. The first included a description of their KB model and key points from the interviews about the strengths and challenges associated with implementing the model. The second outlined teleconference questions as a prompt for subsequent telephone discussions. Participants were asked to discuss these questions with colleagues at their own site who were unable to attend the teleconference so that they could share a broader perspective. The teleconference discussion questions were based on the Stages of Change questionnaire^{3,4} and focused on the impact of the KB study on their organization, possible KB models that would be relevant to rehabilitation organizations and the next steps.

KT Strategies

- *Schedule teleconference meetings in lieu of face-to-face exchanges, to share research evidence with busy administrators and clinicians.*
- *Create user-friendly and appropriately tailored summaries to outline research results and facilitate collaboration.*

Progress to Date

The researchers conducted six teleconferences with 24 participating organizations across the three provinces. All of the teleconferences had at least one representative from each participant groups – administrators, KBs and PTs – and one teleconference had a Ministry representative.

Based on feedback from the teleconferences, the researchers developed a document directly targeting chief executive officers (CEOs) of children’s rehabilitation organizations, as teleconference participants clearly stated that the final decision about funding a KB role would be made by their CEO. In this document, the researchers highlighted the benefits of a knowledge broker for the organization and suggested concrete actions the organization could take to put a KB role into practice. The researchers revised the document with feedback from one CEO, and plan to send it to each CEO and study participant. They also plan to develop additional brief summaries for program managers and one for Ministry decision makers who provide funding to the rehabilitation organizations. In addition, they will write a summary of the teleconference discussions emphasizing things that mid-level administrators and front-line clinicians can do to promote a KB role within their organization. These documents will be made available on the *CanChild* website.

Lessons Learned

The researchers learned a number of important lessons from their KT strategy:

1. Networking between the research team and study participants after the study was completed enhanced their ability to share results and discuss the clinical implications of the findings. Participants’ enthusiasm was rekindled as they reconnected with each other during the teleconferences, and shared their experiences and ideas for moving forward.

Lessons Learned

- *Engaging knowledge users in the KT strategy helps to facilitate change and implementation.*
- *Incorporating stakeholder feedback into dissemination materials ensures a more tailored and relevant product.*
- *Choosing appropriate resources for a KT plan, like teleconferencing, can optimize audience engagement.*

2. Conducting teleconferences was a cost-effective way to bring together multiple perspectives within and between organizations. Administrators, KBs and PTs provided different viewpoints when discussing the results and impact of the study on their organization. Representatives from several organizations helped raise enthusiasm and provided examples of innovative strategies to guide the implementation of a KB role. Further, the discussions illustrated that many organizations have common issues and goals, and that collaboration might be the best way forward.
3. Taking the time to seek and incorporate participant feedback enabled the researchers to create written materials that are more specific and relevant to their target groups.
4. Involving individuals who make funding decisions, such as administrators and government representatives, is key to facilitating change within organizations. Based on feedback from teleconference participants, the researchers will be engaging CEOs and Ministry representatives in their ongoing KT activities. However, they believe it would have been beneficial to include CEOs and Ministry representatives in the teleconferences to allow them to hear the ideas and feel the energy generated during the discussions.

Next Steps

As part of ongoing efforts to implement its end-of-grant KT strategy, the research team intends to:

1. Continue to develop materials for distribution to target audiences, post them on the *CanChild* website and monitor their uptake over time using Google analytics.
2. Conduct telephone interviews with a representative from each organization to determine what changes, if any, have occurred in planning for, or implementing, a KB role since the teleconferences were held in the fall of 2009.
3. Write a summary of what they learned from the telephone interviews and share this information with study participants.
4. Write a journal article describing possible KB models based on experiences from the study and ideas generated during the teleconferences.

The researchers plan to seek further funding to continue to explore the effectiveness of a KB role. During the teleconferences, they heard clear messages that KBs were highly valued and effective in facilitating change. They want to move forward with the ideas expressed about key components of knowledge brokering, such as a regional KB synthesizing evidence and producing materials for use by local KBs. They also want to work with key decision makers to help make this role a reality in children's rehabilitation organizations.

Notes

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- ² www.canchild.ca/en/ourresearch/resources/FINAL2009KBStudyReportVersion3.pdf
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5. RESPONDING TO GAPS IN HIV PREVENTION AND ACCESS TO CARE AMONG WOMEN SURVIVAL SEX WORKERS

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*Dr. Kate Shannon, BC Centre for Excellence in HIV/AIDS;
Division of AIDS, Department of Medicine, University of British Columbia*

Background

In this project, a three-year CIHR-funded community-based HIV research grant was used to examine the health-related harms and barriers to HIV prevention and access to care among women in street-based sex work. The results were published in a series of peer-reviewed publications.¹⁻¹⁰ The grant involved a formal partnership between the BC Centre for Excellence in HIV/AIDS (BCCfE) at the University of British Columbia and the Women's Information Safe Haven (WISH) Drop-In Centre Society, in Vancouver.

The study adhered to participatory-action research principles and methodologies, outlined in peer-reviewed manuscripts co-authored by community and academic partners.^{2,9} Throughout the project, the research team included women with current and former experience as survival sex workers – those who exchange sex for money or other basic necessities such as food, shelter and protection. They played a key role in all aspects of the project, from conceptualization and implementation, to interpretation and dissemination of results.

In addition to the ongoing community engagement and KT strategies adopted throughout the project, the research team implemented a variety of policy and community dissemination strategies, including media releases of their peer-reviewed publications, politically relevant commentaries, and ongoing community consultation and dialogue.

Knowledge Translation Strategy

An effective knowledge translation (KT) strategy was imperative to public health policy and practice in light of evidence of extreme violence and adverse health outcomes, including HIV infection among women in street-based sex work across Canada, as well as court challenges to federal prostitution legislation. The team's end-of-grant KT strategy focused on the dissemination of research results and involved the mutual exchange of knowledge between researchers and knowledge users.

The research team formed a KT steering committee of peers, including sex workers and researchers, to play a key role in KT and community dissemination. The peer group received extensive training on presentation

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KT Goal

Improve health outcomes, including the reduction of HIV infection, for street-based sex workers by contributing research evidence to relevant public health policy and practice.

Audience

- *Policy makers*
- *Police services*
- *Community agencies*
- *Sex workers*
- *Advocacy groups*
- *Legal professionals*
- *Researchers*

KT Strategies

- *Form a KT steering committee of peers to disseminate research findings through plain language summaries and dialogue with the public and the media.*
- *Organize structured community forums to discuss research results and provide knowledge users with opportunities for feedback and interaction.*

development, KT and communication with the media. The research team also developed plain language summaries of findings accessible to the community. A series of community forums were organized and provided a venue to discuss findings, receive feedback and pilot audience-specific actionable messages, such as targeting key policy issues for public dialogue and politically-relevant commentaries. These forums were held during the day at the Downtown Eastside Sex Workers' United Against Violence (SWUAV) Society, and during the evening, at the WISH Drop-In Centre Society. Team members subsequently presented their findings at numerous public events and community venues along with their trained peer researchers,¹¹ and at national and international conferences.

Progress to Date

These KT activities have had critical policy and practice outcomes. Following the presentation of results at a public forum, and dialogue with key stakeholders, Dr. Shannon was asked to submit the peer-reviewed findings as an expert witness in a constitutional challenge of Canada's criminal prostitution legislation initiated by a group of survival sex workers. The findings were also presented at Vancouver City Council in July 2009 as part of a motion to move forward an agenda for reducing harms in the sex industry.

Based on these dialogues and forums, the findings have been used to support the evidence-based need for several community grant proposals aimed at piloting a mobile outreach and HIV prevention model for survival sex workers. Community partners, SWUAV and WISH recently secured funding from the

MacAIDS Fund, with BCCfE serving as research advisor, to develop a targeted peer outreach model for HIV prevention. A second proposal is pending with the Public Health Agency of Canada as part of the AIDS Community Action Program, a Federal Strategic HIV/AIDS initiative. Based on this pilot work, a larger intervention research grant application is also being prepared and will be submitted to research funding agencies such as CIHR and the US National Institutes of Health (NIH).

Impact

- *Research results are being used to support policy and practice decisions as well as grant applications for ongoing community-based HIV research.*
- *By involving relevant stakeholders early in the process, the research team is seeing strong interest and engagement from end users in further applying the resulting evidence.*

In addition, Dr. Shannon and Kate Gibson, co-principal investigator and Executive Director of WISH, brought together sex workers, sex work agency directors, and members of the Vancouver Police Department to develop a more accessible and improved system for monitoring client violence. Specifically, a database manager from BCCfE has developed a 'bad date'

database that is hosted and owned by WISH. This new database is updated and monitored weekly by WISH. BCCfE continues to support WISH by creating monthly summaries that are circulated to sex workers, community agencies and police services. This effort seeks to improve the safety of sex workers, accountability and police response to violence and, ultimately, to reduce incidents involving violent behaviours.

Next Steps

The research team received a five-year CIHR general operating grant to extend its initial work to evaluate the impact of social, physical and structural interventions centered on sexual health, violence and HIV/STI (sexually transmitted infection) risk among female sex workers, both on and off the street. Through this work and its ongoing discussions with the City of Vancouver, the team is well positioned to evaluate the impact of local policy initiatives. Recently it has also been awarded an evaluation contract from Vancouver Coastal Health Authority and Health Canada for an integrated housing and treatment program for women who use drugs and exchange sex.

Notes

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- ¹¹ UBC World AIDS Day, Vancouver, BC (November 2008); HIV Symposium, Northern Health Authority, Prince George, BC (October 2008); SFU Faculty of Health Sciences Rounds, Vancouver, BC (July 2008); "Criminalization of Sex Work" FIRST Public Dialogue, Vancouver Public Library, Vancouver, BC (June 2008); 12th Annual BC Aboriginal HIV/AIDS Conference, Healing Their Spirit, Prince George, BC (April 2008); Women's Health Research Network Summer Institute, Victoria, BC (April 2008); BC Occupational Health and Safety Research Network, UBC, Vancouver, BC (February 2008); BC Centre for Excellence in HIV/AIDS, St Paul's Hospital Rounds, Vancouver, BC (May 2007); 11th Annual BC Aboriginal HIV/AIDS Conference, Honouring the Circle: Their Ways, Their Traditions, Victoria, BC (March 2007); Women's Health Research Network Winter Institute, University of British Columbia, Vancouver, BC (February 2007).

6. BRIDGING MINING COMMUNITY HEALTH AND SUSTAINABILITY

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Janis Shandro, PhD candidate, Norman B. Keevil Institute for Mining Engineering, University of British Columbia, and Doctoral Fellow, Social Sciences and Humanities Research Council of Canada

Dr. Mieke Koehoorn, Associate Professor, School of Population and Public Health, University of British Columbia, and Senior Scholar, Michael Smith Foundation for Health Research

Dr. Malcolm Scoble, Robert E. Hallbauer Chair in Mining and Sustainability, Norman B. Keevil Institute for Mining Engineering, University of British Columbia



Photo of Tumbler Ridge, British Columbia by Malcolm Scoble

Background

This CIHR-funded study on mining and community health was used to investigate the economic, social and health characteristics of British Columbia resource-based communities with a focus on mining from 1991 to 2002. Other types of resource-based communities were used as a comparison group. The project was a collaborative research initiative between the School of Population and Public Health and the Norman B. Keevil Institute of Mining Engineering at the University of British Columbia. Findings revealed that mining communities were more dependent on the mining industry than comparison communities were on their resource industries. They were also less diverse in terms of economic opportunities. Women lacked equal employment and income opportunities in all resource-

KT Goal

Use research evidence to highlight the importance of community health to the BC mining industry and initiate collaboration between stakeholders toward community sustainability planning.

based communities, but this inequality was greater in mining communities. Specifically, there was a large discrepancy between male and female incomes, and women had higher unemployment rates. In all cases, mining communities experienced a sharp reduction in population when a mine closed. In contrast, other

resource-based communities had a steady population, or only experienced a slow decline over time. During periods of falling mining employment, acute cardiovascular disease and mental disorder prevalence rates increased in mining communities, whereas this phenomenon was not observed in other resource-based communities.

Mining represents a key economic driver for British Columbia. The industry is demonstrating a commitment to sustainable development and is beginning to recognize the importance of community well-being. Therefore,

the research team felt that knowledge translation (KT) activities beyond the traditional scope of academic research dissemination would be very timely and valuable to:

- Bring the importance of community health into focus for the mining industry; and
- Present research findings to policy makers, communities and the mining industry for reflection, as they develop strategies for the future of sustainable mining communities.

Knowledge Translation Strategy

In keeping with the KT theory that dissemination must target a variety of audiences,¹ the research team engaged the mining industry, health care providers and municipal government representatives in their KT activities which included:

- A plain language research summary report and its evaluation by Tumbler Ridge community members representing the mining industry, community health services, and local policy makers;
- Presentation of research findings at the Northeastern BC Community Coal Forum on October 8, 2009, held in Tumbler Ridge, British Columbia – a coal mining community; and
- The Mining and Community Health Workshop, held on October 9, 2009 in Tumbler Ridge, to inform decision making and action with research findings. Workshop participants represented the mining industry, the health sector, local policy makers and university researchers.

Audience

- *The mining industry*
- *Municipal government representatives*
- *Health care providers*
- *Community members*
- *Researchers*

KT Strategies

- *Develop a plain language summary to communicate the research results to stakeholders and provide an opportunity for feedback.*
- *Organize a stakeholder workshop to inform decision making and action with research evidence.*

Progress to Date

Knowledge users are driving the delivery of research messages: It was important to ensure that findings and recommendations reported in the research summary were clear, acceptable and relevant to different stakeholder groups. To this end, researchers met with health care providers, community leaders and mining industry representatives from Tumbler Ridge to seek their input. Participants were asked to evaluate the report orally and through a brief written evaluation form, and their feedback was incorporated into the final research summary report.

The involvement of different stakeholders from a well-known BC mining community strengthened research messages to potential knowledge users. The summary report has now been presented to other mining communities participating in the study, the Mining Association of British Columbia and the Ministry of Mines, Energy and Petroleum Resources. It is also available on the Centre for Health and Environment Research and the Norman B. Keevil Institute of Mining Engineering websites.²

Knowledge translation – A platform for collaboration and change: The Mining and Community Health Workshop engaged the community of Tumbler Ridge by using the research findings to develop an action plan. As part of the plan, workshop participants agreed that Tumbler Ridge needed a community sustainability plan. As a first step, researchers were invited to propose a framework for such a plan. Participants also suggested that the process of developing a community sustainability plan would be of value for mining companies in the early phases of planning for a mineral development. The municipality and health care providers supported this suggestion as the process would reinforce early engagement between a mining company and the community.

Impact

- *The KT strategy was a catalyst for developing an evidence-informed community action plan.*
- *Interactions between researchers and stakeholders sparked interest in developing ongoing collaborative relationships to further apply the research evidence.*

Lessons Learned

These KT activities achieved the goal of highlighting the importance of community health to the BC mining industry, and initiated a process of collaboration between the industry, community leaders and health care providers toward community sustainability planning. However, during the Mining and Community Health Workshop, it became apparent that more work was required to fully address some of the research findings. In particular, how the mining industry intends to work with communities prior to and during mineral development; how various departments and levels of government communicate and are ready to assist mining communities in transition; and how mining communities plan for changes that will undoubtedly occur as a result of mineral developments.

Next Steps

Through continued KT activities, the research team hopes that the development of a community sustainability plan will be incorporated into the mine development application phase. This will encourage mining companies to fully engage community leaders early to promote mining community health and sustainability. As this involves collaboration between multiple stakeholder groups, additional activities are planned to expedite the process. This includes meetings with the Mining Association of British Columbia and with mining companies headquartered in Vancouver. Personal contacts with other communities involved in the study and governmental officials are also required, as well as presentations of research findings at international mining conferences.

Very little prior research has been done about the impact of mineral developments on community health and well-being. Based on the study's findings and through related KT activities, the team has determined

that collaborative efforts are required to bring together industry, government and communities to recognize the priority need for enhanced strategic planning that addresses community sustainability and the cyclical nature of mineral developments.

Notes

¹ Canadian Institute for Health Information (2001). *An environmental scan of research transfer strategies*. Ottawa: Canadian Institute for Health Information.

² www.cher.ubc.ca/researchreports/publicationlist.asp and www.mining.ubc.ca/news.php

7. GENAPHA: HARNESSING THE POWER OF THE WORLD WIDE WEB

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Denise Daley, St. Paul's Hospital, Vancouver

Background

In the future, genetic research will inform clinical decision making and personalized treatment options based on individual genotypes. These advances are already on the horizon. The AllerGen Consortium's research is intended to lay the foundation for the development of genetic panels that can determine susceptibility to asthma and predict responses to drug treatments. Their research includes four asthma studies involving 5,565 individuals in Canada and Australia. These individuals were genotyped for 162 candidate genes for asthma and related phenotypes, generating more than 12.3 million genotypes.

To date, the Consortium has published seven manuscripts in leading asthma, immunology and bioinformatics journals. Such traditional dissemination methods are important, but are not ideally suited to the volume of data generated by the AllerGen studies, nor do they facilitate interactions between researchers.

Knowledge Translation Strategy

As the outcome of an international asthma research consortium, these genetic studies needed a knowledge translation (KT) strategy that went beyond traditional methods. The KT plan had to be able to handle, organize and assemble the large amount of data generated by modern genetic studies, and do so in a way that was both easily and widely accessible. Based on these needs, the Genapha website¹ was born.

With traditional methods, only the most statistically significant results can usually be published or presented. In order to make more information available to the scientific community, the Consortium needed to go beyond publishing only significant results. It wanted to reach the widest possible audience, increasing the likelihood of further functional and clinical studies and, ultimately, the application of research into practice.

Three main objectives were initially set for the Genapha website:

1. Describe the AllerGen Consortium teams and study designs.
2. Disseminate association results for candidate gene analyses.
3. Address the public's interest in asthma and the potential impact of genetics on its treatment and management.

Two additional objectives were identified during the development of the website:

1. Better understand the asthma phenotype, specifically symptoms and clinical presentation, and ultimately identify the biological mechanisms that lead to the development of asthma by integrating

KT Goal

Increase the potential impact of genetics by making the large volume of data from genetic studies widely accessible and by facilitating interactions between researchers and knowledge users.

Audience

- *Clinicians*
- *Researchers*
- *General public*

the genetic, demographic, clinical and environmental exposure information with existing knowledge from public databases regarding gene function, genetic pathways and gene ontologies.

2. Expand Genapha beyond a simple data warehouse into a powerful scientific tool that allows visitors to interact with the data and test scientific hypotheses.

The Genapha site needed to be easy to navigate and allow users to identify and retrieve information quickly, so researchers focused on developing effective search tools. To achieve this interactivity, they needed to incorporate their results with existing knowledge. Studies of common, complex diseases have led to a growing number of well-curated databases. However, the information is so abundant that specific searches often

KT Strategy

Develop an accessible and easily searchable website which makes genetic research results more readily available and allows users to interact with the data.

lead to several resources, and collecting the pertinent data manually can be extremely time-consuming. Accordingly, the power of bioinformatics was used to automate the search and retrieval of information from 11 public databases.

The researchers developed new tools and software to address this challenge: Path², a tool to facilitate the investigation of complex diseases, and SLIMS³,

a user-friendly sample operations and inventory management system for genotyping labs. They incorporated these tools into the Genapha website and developed them as software packages to allow other researchers to use them to study complex traits in humans, animals and plants.

Genapha is also a valuable resource for those studying other immunology and inflammatory processes that are likely to share common genetic pathways with asthma.

Progress to Date

Genapha currently supports the dissemination of results from six published scientific papers,^{2,4-8} one accepted paper,⁹ two submitted papers, four papers that are still at the preparation phase and presentations

Impact

- *Website user data indicates that the team is connecting with researchers they would not normally reach.*
- *The development of the website has led to the creation of new tools that can be used to investigate other complex diseases.*

made at 18 international research conferences. Website monitoring shows that, from February 2009 to January 2010, 3,001 users from 48 countries visited Genapha. Fifty-three percent of them returned to access additional information. The Path software and research information areas received the most traffic.

The paper on the Path software was published in print on September 15, 2009 in *Bioinformatics*. According to GenomeWeb, it was one of the top 20 most accessed articles on the web during the month of September and

was written up as a tool-related paper of note.¹⁰ *Bioinformatics* has indicated that, as of December 2009, Path had been downloaded over 3,000 times. These numbers show that the research team is reaching other researchers worldwide.

In addition, 54 organizations have requested permission to link to the Genapha website, including organizations serving asthmatic and allergic patients and their families. Genapha distributes animations



Photo by Dr. Scott J. Tebbutt, University of British Columbia

designed to educate asthma patients and their families which were developed by Dr. Scott Tebbutt with funding from AllerGen NCE. For the future, the researchers hope to expand Genapha's links with patient education and advocacy groups and websites.

Lessons Learned

The research team acknowledges that there is still room for improvement. For example, it is aware that the wider the range of user feedback, the more versatile and effective the tools and approaches can be. While the creation of the website was an interactive process between users and the development team, the test audience came mostly from within the Consortium's own research centre. The research team knows now that input from a broader audience would have been valuable, and one of the biggest challenges it faces is securing that broader audience for further user-testing and development.

Next Steps

The research team is currently working on expanding the Path software to include several new statistical algorithms to analyze genetic pathways and gene ontology networks. The team plans to distribute these algorithms with updated software in Path2. It is also in the process of completing a genome-wide association study. These tools and resources will be added to the Genapha website.

Notes

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8. NEW KNOWLEDGE ABOUT VIOLENCE ACROSS THE LIFESPAN: SHARING THE FINDINGS OF THREE LARGE RESEARCH PROGRAMS

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*Nadine Wathen,¹ Harriet MacMillan,² Marilyn Ford-Gilboe,¹
Christine Wekerle,² Susan Jack² and Shannon Sibbald¹*

¹ The University of Western Ontario

² McMaster University

Background

Family violence is a significant social and health issue. The research teams' goal for this project was to communicate new knowledge emerging from three separate CIHR New Emerging Team (NET) grants¹ using a shared process, with emphasis on synthesizing messages within and between the NETs. The findings from the many projects conducted under the NETs represent a significant body of new knowledge. Most of the projects were initially designed to address specific gaps in clinical practice and health policy development, many with input from stakeholders. The research team wanted to provide decision makers working in the area of family violence with a more coherent "story" about the causes and consequences of, and the health care responses to, violence across the lifespan. This includes establishing links between the different forms of violence exposure and identifying ways to address them in a more coherent manner.

KT Goal

Disseminate synthesized findings from several research teams, providing decision makers with a more coherent picture of the causes and consequences of violence across the lifespan.

Knowledge Translation Strategy

To achieve this goal, the Family Violence Knowledge Exchange Forum² was organized to bring together relevant stakeholders in research, policy, anti-violence advocacy, and health and social service leadership positions from across the country with members of the research teams. This full day event took place in Toronto, Ontario, on January 29, 2009. Approximately 100 participants attended, including 88 stakeholders from outside the research teams. Among them were officials from a number of provincial ministries in Ontario, New Brunswick and British Columbia, as well as leaders and practitioners in health care, social services and the anti-violence community.

Based on feedback from previous knowledge translation (KT) events held by the McMaster research group, the day was structured to optimize dialogue and to focus on how evidence could inform decision making. Each research team presented the most important implications from their studies and then engaged the participants in a dialogue. In small groups, attendees were asked to discuss the implications of the main research findings, including cross-sectoral links and remaining knowledge gaps.

Audience

- *Provincial policy makers*
- *Practitioners*
- *Social services*
- *The anti-violence community*

KT Strategy

Organize a forum structured to optimize dialogue between researchers and knowledge users, with a focus on the implications of research findings and the identification of remaining knowledge gaps.

Rather than having a researcher facilitate each group, each discussion group was provided with questions about what they heard and what they thought they might do with the new knowledge, and researchers circulated among groups to answer questions. Hence, there was less emphasis on presenting research details, and more on synthesized messages and a “hands-off” approach to stakeholder discussion. In order to evaluate the effectiveness of the KT processes in “real-time”, researchers asked permission to record those discussions on tape for later analysis. The teams also presented over

20 posters profiling specific projects, with enough time allotted during breaks for participants to browse them and speak to researchers. The use of posters ensured detailed information was available while providing informal opportunities for stakeholders to engage with researchers.

A full analysis of the meeting evaluation data is underway. However, based on completed evaluation surveys, the goal of research knowledge dissemination and sharing was achieved. The majority of respondents found it valuable to discuss research findings and network with researchers and other stakeholders, and they thought the Forum would influence their decision making in the area of family violence.

Lessons Learned

The three NETs had engaged in varying levels of KT up to the Forum. One interesting issue was that members of the broader research teams who were less familiar with KT found it quite challenging at times to produce concise key messages and make recommendations based on the results. Some presentations were not

Lessons Learned

The research teams found it challenging to strike a balance between providing a diverse audience with clear-cut, synthesized findings while maintaining the rigour and integrity of the research results.

delivered at a level or in a format that stakeholders found useful, and despite careful planning and discussion of the approach beforehand, there were a few ‘lost in translation’ moments. It’s a significant departure for researchers to boil down their results into two or three high-level messages, and there was significant discomfort in presenting these kinds of messages without the justifying data, statistics and graphs. But messages that were too detailed and not linked to recommendations were challenging for people in the audience who just wanted the ‘bottom line’.

On the other hand, the need to synthesize complex and sometimes less than clear-cut findings down to a few sentences can be problematic and risks losing important nuances and caveats about the relevance of current results in the broader picture. The middle space between ‘too much’ and ‘not enough’ research detail is not easy to negotiate, particularly with a diverse audience. The researchers thought this was a clear – but necessary – trade-off in the desire to communicate to all stakeholders at once and not advantage one group over another, while being evidence-based in all messages communicated. This kind of decision is largely driven by the particular field of research and is essentially based on a value judgement on the part of researchers, ideally informed by the interaction with stakeholder-partners, as was the case here.

Next Steps

1. With funding from CIHR and SSHRC, the McMaster research team led by Harriet MacMillan is continuing to assess the dissemination, uptake and use of evidence emerging from the McMaster NET, specifically that which relates to the work on screening women for intimate partner violence in health care settings. By following up with key stakeholders over the long term, it hopes to shed light on the strategies that were most effective in communicating these research results, and whether and how practice and policy are influenced.
2. The University of Western Ontario NET led by Marilyn Ford-Gilboe is engaging in ongoing KT activities as part of its Women's Health Effects Study, including a policy forum held in New Brunswick in November 2009, and others planned for Ontario and British Columbia in early 2010. The inclusion of women who participated in the research as stakeholders in the New Brunswick forum was a novel and very positive approach that had a significant impact on attendees.
3. Researchers from all three NETs now play a lead role in a new CIHR-funded Centre for Research Development in Gender, Mental Health and Violence Across the Lifespan with Harriet MacMillan and Nadine Wathen as co-principal investigators. The PreVAiL Research Network³ brings together a national and international team of researchers, policy makers and other stakeholders to engage in developing a policy-relevant research agenda on gender, violence and mental health. A key focus of PreVAiL will be knowledge translation and exchange of research to practice and policy.

Notes

- ¹ *Violence across the lifespan: A multidisciplinary approach* (H. MacMillan, principal investigator, FRN-NET 54019); *The impact of child maltreatment on adolescent and adult health outcomes* (C. Wekerle, principal investigator, FRN VGH63212), and *The long-term impact of intimate partner violence on mental and physical health of women who have left abusive relationships* (M. Ford-Gilboe, principal investigator, FRN VGH63211).
- ² Funded by a CIHR Meetings, Planning and Dissemination Grant – End-of-Grant Knowledge Translation Supplement.
- ³ www.PreVAiLresearch.ca

9. KNOWLEDGE TRANSLATION IN THE FIGHT AGAINST THE GLOBAL TOBACCO EPIDEMIC

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Geoffrey T. Fong, PhD, University of Waterloo and Ontario Institute for Cancer Research

Background

Tobacco use is the most prevalent cause of death in the world, accounting for about five million casualties each year. Whereas 100 million people died of tobacco use in the 20th century, an estimated one billion people are projected to die in the 21st century. The world's first health treaty, the WHO Framework Convention on Tobacco Control (FCTC), was developed in response to the tobacco epidemic. The FCTC identifies policies that ratifying nations – now totalling over 160 – must implement, such as enhanced warning labels, smoke-free laws, advertising bans and higher taxes. The FCTC promotes itself as an evidence-based treaty, yet at its inception, there were almost no international comparative evaluation studies of tobacco control policies.

KT Goal

Improve the effectiveness of global tobacco control policies by providing countries with research-based feedback stemming from policy evaluation.

Geoffrey T. Fong, Professor of psychology at the University of Waterloo, launched the International Tobacco Control Policy Evaluation Project (ITC Project) in 2002, the first international research program for the systematic evaluation of FCTC policies at the population level. The ITC Project started with four countries – Canada, the United States, the United Kingdom and Australia – and received major funding from each.¹ The project has expanded and the research team is now conducting longitudinal cohort surveys in 20 countries, representing over 50% of the world population, as well as 60% of smokers and 70% of tobacco users worldwide. Today, the ITC Project remains the only research program focused on the evaluation of FCTC policies.

A key objective of the ITC Project is to provide rapid translation of knowledge from evaluation studies to the global tobacco control community, including policy makers, researchers and advocacy groups. This goal is achieved by communicating results through presentations and briefings at international tobacco control meetings and conferences, and in scientific journal articles.

Knowledge Translation Strategy

In parallel with these more traditional dissemination efforts, the team drafted and disseminated plain language summaries of its key findings, incorporating input from knowledge users. With funding from CIHR² and other sources, it published a National Report for the France Project and five brief National Summaries for China, France, Germany, the Netherlands and Thailand.³

Audience

- *Policy makers*
- *Researchers*
- *Tobacco control advocates*

In addition, it produced the ITC Tobacco Warning Labels Report to present its findings to the 2009 World No Tobacco Day (WNTD), which focused on pictorial warnings. The Report was presented and distributed

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at the event and at multiple WNTD media events throughout the world. It was translated in Chinese by the China Project team and distributed widely at a press conference given by its principal investigator, Dr. Jiang Yuan, Deputy Director of the National Office of Tobacco Control at the Chinese Center for Disease Control and Prevention.

There are numerous examples of evaluation results disseminated through the Summaries and the France National Report to promote strong evidence-based policies under the FCTC. For example, the France National Report describes survey findings that support France’s 2008 total smoking ban in cafés, bars and restaurants. The ban has been a success both in dramatically reducing smoking in bars and restaurants and in leading to a significant increase in support for a total ban on smoking in these venues, even among smokers. The Thailand Summary provides evidence that Thailand’s introduction of graphic warnings in 2006 has made smokers more likely to think about the health risks and be more motivated to quit. The China Summary describes research demonstrating that China’s text-only health warnings on the side of cigarette packages are not effective, and that the majority of Chinese citizens support policies seeking to completely ban smoking in public places. The Netherlands and Germany Summaries present clear findings

that less restrictive and weakly-enforced smoking bans in bars and cafés have had less success than in Ireland and France, where strong policies were effectively implemented.

The guiding framework for these knowledge translation (KT) products closely follows the five principles for successful KT identified in the Foreword to CIHR’s *Knowledge Translation Casebook*, which emphasizes the participation of knowledge users.⁴ A major factor in the success of these dissemination efforts has been the close partnership with ITC country

teams, including key decision makers for tobacco control. Country partners have provided essential guidance in ensuring that graphic images were culturally appropriate and messages accurately translated into the host country language, and that the interpretation of findings effectively addressed national tobacco policy needs. As a result, ITC documents have been brought to the attention of tobacco control policy makers at the highest level.

For example, because of the strong partnership developed with France’s Health Ministry, the Minister of Health and Sport wrote the Foreword to the France National Report, which also displayed her signature and official portrait. At a press conference held on the first anniversary of the ban, she presented the evaluation of the smoking ban published in the ITC France Summary. The Health Ministry also provided French translation and printing of the National Report and Summary. The France National Report is an official French Government document that is posted on the website of the Ministry of Health and Sport. Both the National Report and the Summary have been disseminated at key international conferences attended by tobacco control experts from around the world and at meetings focused on the development of protocols and guidelines.

KT Strategy

Knowledge user participation in the production of plain language summaries helped ensure that materials were properly translated and culturally appropriate, and addressed the specific policy needs of the country in the area of tobacco control.

Impact

The research team has shared the policy recommendations arising from the ITC Project Reports and Summaries with government officials and other stakeholders at face-to-face meetings and in teleconferences involving numerous countries around the world.

The team has used these summaries and reports in discussions with government representatives to help shape new FCTC policies, particularly in the area of warning labels. For example, at the Third Conference of the Parties of the FCTC, the South Korean delegation expressed concerns that pictorial warnings might have adverse effects on smokers. Dr. Fong presented findings from several ITC studies on warning labels, including data on Korea, to reassure the Korean delegation that graphic warnings were indeed effective and did not have adverse effects. Following the presentation, the Korean delegation announced that it fully supported pictorial warnings.

Impact

- *The team's research summaries have become powerful tools, supporting policy recommendations to government officials.*
- *Several countries have used the evidence-informed recommendations to strengthen national tobacco control initiatives.*



ITC Tobacco Warning Labels Report Cover (May 2009)
Available at www.itcproject.org

The findings presented in the ITC Tobacco Warning Labels Report about the importance of placing warnings on both the front and the back of cigarette packages have influenced policy decisions in Brazil. That country has implemented some of the most vivid and emotionally arousing pictorial warning labels in the world. However, these labels only appear on the back of packages, where smokers are much less likely to see them. Based on ITC findings pointing to the poor salience of tobacco warning labels in Brazil, the Brazilian Government has decided that, going forward, the labels will have to be printed on both the front and the back of cigarette packages.

ITC evaluations of smoke-free policies around the world, disseminated in the Summaries and National Reports in the form of cross-country comparisons, have been instrumental in supporting stronger and more comprehensive smoke-free laws in a number of countries. The WHO Tobacco

Free Initiative has recognized the ITC Project Summaries as *“excellent examples of how research findings can be disseminated in ways that will be useful to policymakers and other nonresearchers in the tobacco control community... those dissemination products will play an important role in shaping the nature of FCTC policy implementation throughout the world.”*

As of October 22, 2009, the France National Report and the Summaries had been distributed to close to 1,000 government officials, NGO personnel, researchers and over 100 other tobacco control knowledge users. There have been 6,847 visits to the ITC website and 2,024 downloads of documents.

The ITC Project dissemination strategy and the dissemination products created and posted on the ITC website and published in printed reports have been highly successful in effectively communicating research results, policy implications and recommendations to tobacco control policymakers all over the world.

Next Steps

The research team is conducting its most recent projects in Bangladesh, Brazil, Mauritius and Bhutan. The challenge is to expand the dissemination of its findings to these and other low- and middle-income countries, where the implementation of strong, evidence-based policies is most urgently needed.

Notes

- ¹ Funded in Canada by the Canadian Institutes of Health Research, the Canadian Tobacco Control Research Initiative, the Centre for Behavioural Research and Program Evaluation, the National Cancer Institute of Canada, the Canadian Cancer Society, the International Development Research Centre, and the Ontario Institute for Cancer Research; in the United States by the National Cancer Institute, the Robert Wood Johnson Foundation, and the American Cancer Society; in the United Kingdom by Cancer Research, and the Scottish Executive; in Australia by the National Health and Medical Research Council, and the Commonwealth Department of Health and Ageing.
- ² Funded by a CIHR Meetings, Planning and Dissemination Grant – End-of-Grant Knowledge Translation Supplement.
- ³ All reports are available on the ITC Project website (www.itcproject.org).
- ⁴ Canadian Institutes of Health Research (2008). *Knowledge to Action: A Knowledge Translation Casebook*. Ottawa: CIHR.