how we work together

THE INTEGRATED KNOWLEDGE TRANSLATION RESEARCH NETWORK CASEBOOK

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IKT Research Network

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FOREWORD

Anita Kothari

The Integrated Knowledge Translation Research Network (IKTRN) is pleased to present the second volume of our integrated knowledge translation (IKT) casebook series. These seven cases demonstrate how researchers are partnering with knowledge users before, during and after a research project. In other words, how IKT happens in real life. The cases help build our knowledge about IKT by challenging and then evolving existing theory-based literature.

In various ways, most projects described in this volume included patients or laypersons as research partners. Some cases described patients as being part of local implementation teams (Gifford, Lewis, Poole), while Banner *et al.* described how patients played a critical role in developing a funding application. Sometimes patients or laypersons were the only research partners. In other cases, researchers worked with patients, laypersons, clinicians, community service providers or other key stakeholders. In all cases, consultations were also carried out with external stakeholder committees or networks who were not involved in the operational aspects of the research but provided valuable input to the research team.

The cases help build our knowledge about IKT by challenging and then evolving existing theory-based literature.

Plamondon *et al.* provided a perspective on working together that is not usually seen in the IKT literature. Her case had an international rather than a local focus. Knowledge user partners came from the global community, including researchers, funders, policymakers, administrators and practitioners. The team developed normative values using deliberative dialogues to guide global health research in Canada.

Case authors offered some interesting views on the challenges of knowledge user engagement using IKT approaches. Not surprisingly, a few mentioned the importance of having financial resources to enable engagement and team-building. They also noted how critical it is to fully support non-researchers to participate. This support goes beyond money. For example, it is important to ensure that all team members understand the purpose of the research. Poole *et al.* and Letourneau *et al.* build on the idea of support by recommending that roles, progress, action items and time commitments be clearly articulated from the beginning and throughout the project. Thinking forwards, Dunn and colleagues pointed to the need to identify new and feasible ways of engaging a wider group of knowledge users when only a few can be on the research team.

Finally, authors noted that actual or perceived power imbalances between research team members could interfere with the smooth functioning of the research, including effective decision-making. To overcome this challenge, Lewis *et al.* followed up with patients and their family members by phone after observing that clinicians had dominated a previous discussion; this allowed patients and family members to contribute their perspectives to the conversation. Gifford *et al.* described a collaboration between researchers and members of a Mohawk community, where mitigating power imbalances meant that the researchers needed to be acutely aware of the cultural dynamics underlying individual and community needs. Further understanding of the sources of power and how to ensure equitable distribution of power during an IKT relationship is sorely needed.

We hope you enjoy this collection of cases. As always, we are open to hearing your reactions after reading them.

The experience of using an integrated knowledge translation approach to develop, implement and evaluate an audit and feedback system in Ontario maternal-newborn hospitals

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Keywords: audit and feedback; dashboard; maternal-newborn; mixed-methods; integrated knowledge translation

BACKGROUND

Project

Audit and feedback compares health-care provider practice to evidence-based benchmarks with the aim of improving clinical practice and related outcomes.[1] Evidence from a Cochrane review[1] supports use of audit and feedback as an effective strategy to improve practice, and a number of studies suggest that use of a dashboard may improve quality of care and patient outcomes.[2-5] In Ontario, wide variation in clinical practice and patient outcomes exists in maternal-newborn care. For this reason, the Better Outcomes Registry & Network (BORN) Ontario developed, implemented and evaluated an electronic audit and feedback system, the Maternal Newborn Dashboard, in all hospitals providing maternal-newborn care in Ontario. The dashboard was designed to facilitate improved maternal-newborn care by visually indicating evidence-practice gaps related to six selected key performance indicators and providing direction for practice change.

Knowledge users

The target audience for the audit and feedback system was (1) health-care providers, (2) decision makers, and (3) leaders of maternal-newborn care in Ontario hospitals. As such, the knowledge users engaged in this project included representatives from these three groups (Table 1).

DESCRIPTION OF IKT ACTIVITIES

We adopted an integrated knowledge translation (IKT) approach to guide two phases of the project. Phase 1 involved the development of the dashboard (the innovation, the audit and feedback system, to be implemented). Phase 2 involved the evaluation of the effectiveness of the dashboard in terms of improving practice.

Establishing the IKT partnership

Members of the IKT partnership were nominated following a call to join the provincial Maternal Newborn Outcomes Committee. To fulfill the membership requirements, an additional call was extended to the broader BORN community. Committee members were chosen based on their clinical expertise and experience with quality improvement in their maternal-newborn settings, which covered all levels of care. Some of the partnerships established during the dashboard development phase carried forward to the evaluation phase with stakeholders participating through all phases of the project (Table 1).

Table 1. Project phases and team members

Phase	Team * = Knowledge user
Development	Dashboard development committee • *Obstetrician (OB) / Maternal Fetal Medicine (MFM) specialist (n=3) • *Neonatologist (n=2) • *Midwife (n=1) • *Nurse (n=3) • *Pediatrician (n=1) • *Epidemiologist (n=4) • KT scientists (n=1) • Health technology expert (n=1) • Health economist (n=1)
Evaluation	Study team • *Midwife (n=1) • KT scientists (n=3) • *Epidemiologists (n=2) • *Neonatologist (n=1) • Nurse scientists (n=3) • *OB/MFM (n=2) • Biostatistician (n=1) • Trainee - Master's (nursing) (n=2) • Trainee - PhD (epi) (n=1) • Research staff (n=2) Study participants • *Dashboard development team (n=15) • *Dashboard implementation team (n=13) • *Ontario hospital health-care providers and leaders (n=107)

Dashboard development phase (2010-2012)

To ensure the dashboard was an effective tool to facilitate practice change, it needed to be defensible, perceived as credible and seen as an authoritative source of information. Therefore, we used a rigorous development process to ensure the credibility of the dashboard.[6] We followed the *BORN Ontario Dashboard Development Roadmap*[6] to guide key performance indicator selection, dashboard design and testing, implementation, and post-implementation monitoring and evaluation. This involved assembling an interprofessional Dashboard Development Committee with combined membership of researchers and knowledge users (clinicians and decision makers) from across the province.

The development process first involved brainstorming, consulting with clinical experts and scanning the literature to identify potential key performance indicators that reflected health-care quality domains (i.e., appropriate and effective care) that were clinically meaningful, feasible to measure and actionable at the point of care. We used a modified Delphi process with deliberative dialogue, consensus building and priority setting with all team members to select the final list of indicators and set evidence-based benchmarks. We collaborated with the Knowledge Synthesis Group at The Ottawa Hospital Research Institute to develop systematic review protocols and evidence summaries for each of the key performance indicators. Members of the development committee then collaborated with the BORN Report Development Team to co-create the specifications for the dashboard so the functional report could be built within the BORN Information System. Once the report had been created, but prior to provincial launch of the dashboard, we pilot-tested functionality with a small group of external hospital users. Members of the development committee then collaborated with the leadership at BORN Ontario to co-create the implementation plan.

To support implementation, we struck a small working group who met regularly, followed standard BORN protocols for report release, and co-created a variety of communication and education strategies. For example, to increase awareness and knowledge of the use of the new dashboard, we developed briefing notes, newsletters, targeted messaging and training webinars to communicate to hospital staff at multiple levels (CEOs, directors, managers, BORN champions, etc.). The dashboard was launched in November 2012 and remains active.

Dashboard evaluation phase (2014-2017)

We also used an IKT approach to develop a research protocol to evaluate the effectiveness of the dashboard. The combined expertise within this interprofessional group was instrumental for the co-creation of the study design, data collection, analysis, interpretation of results and dissemination of the study findings. As a result of these collaborative efforts, we obtained provincial and federal funding to conduct a rigorous mixed-methods evaluation to assess the effect of the dashboard on improving clinical outcomes and to explain variability in improvements between hospital sites. Throughout the three-year study, members of the research team met regularly to deliberate on issues and to develop resources needed to guide various phases of the study. Regular full team and small working group meetings with deliberative dialogue, iterative problem solving and consensus building to facilitate decision-making were fundamental components of the IKT approach.

Lessons learned

Throughout this project we learned several valuable lessons about using an IKT approach to develop, implement and evaluate a new innovation. These learnings came from formal data collection activities embedded within our dashboard evaluation study[7] and team member reflections at the end of the project.

Benefits and facilitators to using IKT for our project

From our key stakeholder survey, we found that all respondents were very satisfied or satisfied with the process used and most respondents agreed that the process resulted in:

- Essential stakeholders being involved in the key performance indicator and benchmark setting phase (91 per cent), dashboard design and testing phase (86 per cent) and the implementation phase (62 per cent);
- Sufficient communication with sites to successfully implement the dashboard (77 per cent);
- Sites being very prepared or prepared for the implementation of the dashboard (62 per cent).

Key factors that facilitated the use of an IKT approach included:

1. Organizational capacity and infrastructure to enable knowledge user engagement in co-producing the dashboard, including a knowledge translation champion from BORN Ontario that facilitated collaboration with external advisory groups, the BORN teams, the research team and the external stakeholders.
2. Pre-existing relationships and partnerships from previous research projects and clinical practice initiatives, which facilitated the working group's ability to achieve the objectives of each phase.
3. Some members of the research team were also clinicians embedded within the hospital settings where the dashboard was implemented. They contributed insight into the political, organizational and individual level-factors and competing priorities that could potentially be barriers or enablers to uptake of the dashboard in clinical practice.

Challenges / barriers to using IKT for our project

We observed several challenges that could have implications for future IKT initiatives (Table 2):

- Achieving consensus: Using a true consensus process on an interprofessional team is difficult when there are perceived/actual power imbalances.
- Time: The key performance indicator selection process required more time than was originally anticipated. It takes time to actually retrieve and explore the evidence, discuss clinical practice issues, analyze data and achieve consensus to prioritize key performance indicators appropriately. In addition, the fact that members

Table 2. Challenges in using IKT approach with illustrative quotes

Identified challenge	Illustrative quotes
Achieving consensus	The biggest challenge in my opinion was in setting benchmarks, particularly when it required greater reliance on expert opinion. I think that the benchmark set for [name of indicator] was much higher than is actually ideal/achievable because a lower rate was not perceived as being palatable to some provider groups - some voices carried greater weight than others in reaching 'consensus'. *(Dashboard committee member)*
Time	[Dashboard development] has taken over two years so the timelines are so long that some of the evidence and best practices could change before [the dashboard is] even released. *(Dashboard committee member)*
Engaging all stakeholders	Although we worked with an advisory group of clinical experts during the key performance indicator selection for each of the dashboards, and sought external feedback to validate the high priority items identified, there is always an issue trying to balance the details of exploratory work with sufficient opportunity for broad input from others and not end up continuously going back to the drawing board to start the process again. *(Dashboard committee member)*
Making the IKT process transparent	Your physician base in picking your data was not big enough and it wasn't people who are savvy and clinically based. I mean you might have had a whole bunch of research brains but if they aren't in the clinical field then it's the same rift that we've always had…*(End-user not on dashboard committee)*

of the interprofessional committee were all volunteers from different organizations and had competing priorities within their own work environments made scheduling meetings a challenge.

- Engaging all stakeholders: Despite developing a large and diverse interprofessional provincial committee, it is impossible to include all end-users in the development and implementation process and this ultimately affected user buy-in. There is a need to strike a balance between broad knowledge user representation to ensure innovation relevancy, credibility and buy-in, while limiting the size of the team to maintain efficiency.
- Making the IKT process transparent: Despite a highly coordinated communication effort and BORN resources to support this project, some end-users lacked knowledge about the dashboard itself and the process used to develop it, which limited use in clinical practice. For example, during our case study visits, some participants doubted the clinical relevance of the dashboard indicators and the accuracy of the benchmarks, especially when they believed that they were selected without adequate clinical input. This doubt subsequently led to some sites not being fully engaged with the clinical changes being targeted, which influenced their use of the dashboard.

IMPACT AND IMPLICATIONS

Based on our experience with the dashboard project, there are three key recommendations we would consider for future IKT projects:

- Ensure broad knowledge user representation: A key learning was the need to find new and feasible ways to engage a broader group of end-users in future dashboard developments, and to establish criteria a priori to ensure the best and most representative knowledge users are selected. Factors to consider include clinical, decision-making and research expertise, as well as connectedness within the clinical community

and the motivation and availability to regularly contribute.

- Ensure protected time for IKT work: It is important to consider and acknowledge the time it takes to engage multiple knowledge users in the IKT process, to establish rules of engagement for how the group will function and decisions will be made, and to build adequate time into project and research timelines to allow this interaction to happen.
- Ensure transparent communications about your IKT process: While there is a need to ensure effective communication amongst the project team, it is also essential to ensure sufficient communication to stakeholders and end-users not involved in the IKT process to optimize buy-in. This issue reflects the challenge of ensuring communication is sent to the right knowledge user at the right time and gets disseminated within the organization appropriately. Transparent communication to non-participants of the original IKT process is key to successful dissemination and implementation since it is impossible to include all end-users in the planning process, and staffing changes occur over time.

From our study we found that two years after the implementation of the dashboard in Ontario hospitals, there were statistically significant improvements relative to baseline in four of the six key performance indicators.[8] While we cannot directly attribute these positive changes in clinical practice to IKT alone, based on feedback from committee members, study members and end-users, the IKT approach used certainly contributed to developing and implementing a product that was perceived as credible, relevant and useful by many health-care providers and administrators.

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REFERENCES

1. Ivers N, Jamtvedt G, Flottorp S, Young JM, Odgaard-Jensen J, French SD, et al. Audit and feedback: effects on professional practice and healthcare outcomes. *Cochrane Database Syst Rev*. 2012;6:CD000259.
2. Morgan MB, Branstetter BF, Mates J, Chang PJ. Flying blind: using a digital dashboard to navigate a complex PACS environment. *J Digit Imaging*. 2006;19(1):69–75.
3. Rioux C, Grandbastien B, Astagneau P. Impact of a six-year control programme on surgical site infections in France: results of the INCISO surveillance. *J Hosp Infect*. 2007;66(3):217–223.
4. Zaydfudim V, Dossett LA, Starmer JM, Arbogast PG, Feurer ID, Ray WA, et al. Implementation of a real-time compliance dashboard to help reduce SICU ventilator-associated pneumonia with the ventilator bundle. *Arch Surg*. 2009;144(7):656-662.
5. Roberts DH, Gilmartin GS, Neeman N, Schulze JE, Cannistraro S, Ngo LH. Design and measurement of quality improvement indicators in ambulatory pulmonary care: creating a "culture of quality" in an academic pulmonary division. *Chest*. 2009;136(4):1134–1140.
6. Sprague AE, Dunn S, Fell D, Harrold J, Walker M, Kelly S, et al. Measuring quality in maternal-newborn care: developing a clinical dashboard. *J Obstet Gynecol Canada*. 2013;35(1):29–38.
7. Reszel J, Dunn S, Sprague AE, Graham ID, Grimshaw JM, Peterson WE, et al. Use of a maternal newborn audit and feedback system in Ontario: a collective case study. *BMJ Qual Saf*. 2019; 28(8):635-644.
8. Weiss D, Dunn S, Sprague A, Fell DB, Grimshaw J, Darling E, et al. Effect of a population-level performance dashboard intervention on maternal-newborn outcomes: an interrupted time series study. *BMJ Qual Saf*. 2018; 27(6):425-436.

Development of a patient decision aid to accept or decline implantable cardioverter-defibrillator replacement: An example of integrated knowledge translation in PhD research

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Keywords: implantable cardioverter defibrillator; patient decision aid; shared decision-making; integrated knowledge translation

BACKGROUND

The implantable cardioverter-defibrillator (ICD) is a device that is surgically implanted for the treatment of sudden cardiac arrest. ICDs are potentially life-saving, but they are also life-altering. Every five to seven years, an ICD requires surgical replacement to maintain normal function. Until recently, patients automatically received replacements. Yet, for many reasons, it is a decision worthy of deliberation as it has two justifiable options: to replace or not to replace the ICD. The benefits and burdens of having it replaced may be valued differently from one individual to another, or by the same individual at different points in time. We conducted a needs assessment in a Canadian tertiary care centre with patients who had at least one ICD replaced and clinicians involved in the care of patients receiving ICD replacements.[1] We identified a gap in practice: 52 per cent of patients were not aware of the option to accept or decline ICD replacement and 27 per cent of these patients would have considered non-replacement. Most patients wished for information and involvement in the decision-making process. All clinicians agreed that greater patient involvement at ICD replacement is needed.

Clinical practice guidelines acknowledge the preference-sensitive nature of ICD therapy and recommend individualized counselling to facilitate shared decision-making when facing ICD-related decisions.[2–4] Shared decision-making can be facilitated by patient decision aids (PDAs) as evidence-based tools that present balanced facts about a condition, treatment options, and the benefits and harms of each option.[5] PDAs allow patients to consider what is important to them, guide them in the process of decision-making and help them establish their preferred option.

We used an integrated knowledge translation (IKT) approach to develop a PDA for patients facing ICD replacement and a plan for its implementation in an interprofessional ambulatory care cardiac device clinic in a tertiary care Canadian hospital.

DESCRIPTION OF IKT ACTIVITIES

We used two IKT approaches throughout our PDA development process: a steering committee and broad engagement via interviews. To begin, a steering committee composed of a multidisciplinary team of knowledge users was established to support the PDA development process. The committee included the director of the arrhythmia service, the ambulatory device clinic nursing manager, a device clinic registered nurse, expert researchers in PDA development, two patients who had previously undergone ICD

replacement and the spouse of a patient with an ICD. Our methodology for PDA development was guided by a systematic process following the International Patient Decision Aids Standards, which advises steering committee formation and testing with patients and clinicians to verify comprehensibility, acceptability and usability of the PDA.[6]

The steering committee met twice in person, with exchanges by email and telephone in between. Just ahead of our first meeting, the doctoral student met with the patients and family members to provide an overview of the meeting and explore expectations. During the meeting, stakeholders shared ideas on PDA format, content, presentation of probabilities, potential distribution plans and the interview guide in preparation for broader end-user engagement. While the conversation was mostly driven by health-care professionals and researchers, the patients and spouse did contribute on occasion. Given this imbalance, the doctoral candidate individually contacted the patients and family member by telephone a few days later to review any additional feedback that may not have been shared during the meeting. This proved to be an important step. Not only did stakeholders share additional feedback on PDA content and proposed distribution plans, but they also provided feedback on the structure of the meeting, with emphasis and appreciation for the pre-meeting huddle and de-briefing.

Once a revised prototype was approved by the steering committee, we sought broad end-user feedback on relevance, usability and implementability. An external review of the PDA format and content, including the probabilities of risks and benefits, was conducted by five expert Canadian cardiac electrophysiologists. Next, we conducted 16 interviews with 18 end-users representing various disciplines and professions (e.g., registered nurses, cardiac electrophysiologists, advanced practice nurses, palliative care specialists, psychologists) and patients and family members. End-users were asked to provide feedback on the PDA and how best to implement it in clinical practice. Once interviews were completed, all members of the steering committee met in person to analyze and interpret the findings.

The PhD candidate drafted abstracts for national and international conferences, and a manuscript describing our development process and implementation planning results was shared and approved by all steering committee members. All members accepted an offer to be listed as authors.

IMPACT AND IMPLICATIONS

In total, we consulted with seven out of eight (88 per cent) cardiac device clinic registered nurses and four out of eight (50 per cent) cardiologists with a specialty in cardiac electrophysiology — all of whom work within the ambulatory clinic in which PDA implementation is intended. This was important as they described current clinic workflows and provided expertise on the context. The involvement of the director of the arrhythmia service and the ambulatory device clinic nursing manager was also important given their ability to influence integration of this new intervention into the clinical environment. Patients and family representatives provided valuable insights. However, the steering committee acknowledged that their contributions may not be fully representative of all individuals' needs. Hence, we interviewed additional patients and family members as part of our broad end-user consultations.

As a result of this work, process changes related to ICD replacement have occurred. A predetermined ICD battery voltage was selected as the trigger to increase the frequency of clinic visits for close monitoring of battery status. Previously, this frequency increase was left to the

discretion of the clinician. When this pre-specified voltage is reached, the registered nurse and physician now ensure that a recent electrocardiogram (ECG) is performed, thereby offering a more complete clinical picture to inform the ICD replacement decision-making process. While not yet standardized, device clinic clinicians can, on occasion, inform patients of the option of ICD replacement, particularly if there is not a strong indication for re-implantation according to clinical practice guidelines. Nurses are now more comfortable initiating these conversations with patients - an outcome which the IKT approach may have influenced. These changes in clinic processes and increases in self-efficacy demonstrate the team's commitment to facilitating quality decision-making, and allowing for unrushed deliberation and informed decision-making about ICD replacement.

A preliminary evaluation of the PDA revealed that it is feasible to deliver the intervention, and that it was used by patients and clinicians as intended. Further, the decision-support intervention led to better knowledge and has the potential to improve ICD replacement decision quality (ClinicalTrials.gov # NCT02668900). However, we did not evaluate the IKT process. Hence, we cannot say with certainty that outcomes and current processes are due to the IKT approach. What remains unclear is whether or not our patient/family steering committee representatives *perceived* themselves as decision makers in the research process. Once research activities are complete, we would consider an opportunity to solicit their perspectives on this matter and identify areas for improvement.

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REFERENCES

1. Lewis KB, Nery PB, Birnie DH. Decision making at the time of ICD generator change: patients' perspectives. *JAMA Intern Med*. 2014;174(9):1508–1511.
2. Bennett M, Parkash R, Nery P, Sénéchal M, Mondesert B, Birnie D, et al. Canadian Cardiovascular Society/Canadian Heart Rhythm Society 2016 implantable cardioverter-defibrillator guidelines. *Can J Cardiol*. 2017;33(2):174–188.
3. Lampert R, Hayes DL, Annas GJ, Farley MA, Goldstein NE, Hamilton RM, et al. HRS expert consensus statement on the management of cardiovascular implantable electronic devices (CIEDS) in patients nearing end of life or requesting withdrawal of therapy. *Heart Rhythm*. 2010;7(7):1008–1026.
4. Yancy CW, Jessup M, Bozkurt B, Butler J, Casey DE, Drazner MH, et al. ACCF/AHA guideline for the management of heart failure: a report of the American College of Cardiology Foundation/ American Heart Association Task Force on practice guidelines. *Circulation*. 2013;128(16):e240–327.
5. Stacey D, Légaré F, Lewis K, Barry MJ, Bennett CL, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2017;4:CD001431.
6. Coulter A, Stilwell D, Kryworuchko J, Mullen PD, Ng CJ, Van Der Weijden T. A systematic development process for patient decision aids. *BMC Med Inform Decis Mak*. 2013;13(Suppl 2):S2.

Developing and implementing culturally safe cancer survivorship strategies with First Nations peoples

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Keywords: First Nations cancer survivorship; integrated knowledge translation

BACKGROUND

Cancer amongst Indigenous* people in Canada is increasing faster than overall Canadian rates.[1-3] Advancements in cancer survivorship care have shown that holistic approaches incorporating regular monitoring for early detection and interventions tailored to specific needs can increase survival rates and enhance the quality of life for people with cancer.[4-8] However, available interventions predominantly target white, urban, middle-class people, and health-care services in Canada have failed to provide culturally safe and effective cancer survivorship supports for First Nations people.[9,10] The lack of action to address the unique survivorship needs of First Nations people has been metaphorically referred to as "falling through the cracks."[10] Moreover, few approaches have considered the intersections of culture, poverty, discrimination and marginalization that contribute to low health-care utilization.

With funding from the Canadian Cancer Society our research team collaborated with First Nations and Métis people in five communities across Canada between 2013 and 2016 to understand the unique cultural needs and experiences of cancer survivorship. Findings are publicly accessible through a YouTube video titled *Finding Strength Together* (available here†), and include themes related to: (1) navigating healthcare; (2) spirituality and ceremony; (3) land, nature and traditional healing; (4) sharing and creating; and (5) finding strength together. Committed to working together further, study participants from one of the participating communities, Mohawk Nation at Akwesasne, partnered with the research team to co-design a new study that addresses the health-care needs identified in the video. Specifically, we used an integrated knowledge translation (IKT) approach to develop culturally safe cancer survivorship interventions for the community. The overall purpose of our study was to improve cancer survivorship experiences with First Nations people (CIHR #356773); specific research objectives were to develop, implement and evaluate cancer survivorship strategies with Mohawk First Nations people.

DESCRIPTION OF IKT ACTIVITIES

Our IKT approach was informed by theoretical underpinnings of Indigenous knowledge translation, which recognizes the long and established history First Nations people have with translating their own knowledge into action. Shared ownership, continued open consent,

* The term "Indigenous" denotes the original inhabitant of a country regardless of its borders, and in the Canadian context, refers to First Nations, Inuit, and Métis.

† https://www.youtube.com/watch?v=TYtDsdlKlJg

honouring traditions and power sharing were foundational to our IKT approach, as we collaboratively situated western research knowledge alongside First Nations knowledge rooted in spirituality, connectedness, traditions, holistic healing and reciprocity to the land.

The IKT strategies began with establishing a community-based advisory group that worked with the non-Indigenous researchers (herein named the IKT research team) to determine the cancer-survivorship strategies to be implemented in the health department and wider community. The advisory group (n=8) consisted of cancer survivors, family members, direct care providers (medical doctor and nurses), traditional healers, Elders, and the health department director and manager. One of the university-based researchers and the manager of the health department co-facilitated all meetings with the IKT research team.

Trust and respect were central to establishing the IKT partnership. This included acknowledging the historical trauma of colonization, marginalization and ongoing racism toward First Nations peoples in Canada. Furthermore, shared data ownership and continued open consent were revisited at the beginning of each meeting to establish a safe space for collaborating and developing strategies to address community needs. During the first meeting of this collaboration, the IKT research team watched the *Finding Strength Together* video developed in our first study, stopping to discuss culturally safe approaches that could address the experiences identified in the video. We also discussed goals and expectations for the project and how we would work together to co-create knowledge that honoured traditional ways. Additionally, a name for the study was established in Mohawk — *To:sha Enhshatsheia:ron*, which translates to *Don't be shy.* The results of these discussions were documented in meeting notes and distributed to the IKT team for revisiting at subsequent meetings.

Throughout the meetings, we engaged in culturally relevant forms of communication and oral traditions, which included opening and closing ceremonies with traditional teachers and Elders, talking circles and stories. A total of 16 face-to-face meetings were held over 14 months in the community, where we integrated traditional knowledge and western research-based knowledge to develop culturally safe and meaningful approaches to cancer survivorship for the community.

The IKT research team determined early on the outcomes and dissemination products of the research. In addition to the project resources and timeframe, a menu of impacts and outcomes was discussed, and the final outcomes were chosen based on the community's values, priorities and feasibility, as well as the research team's responsibilities to the funding agency. The community members identified a lack of knowledge about cancer and survivorship supports, problems navigating the health-care system and the need to break down the culture of silence surrounding cancer. Final research products included a series of short videos that address the stigma of cancer and a community-specific cancer booklet entitled *Strengthening My Healing Journey* to be distributed by the health centre.

IMPACT AND IMPLICATIONS

While the research is still underway and the effectiveness of the IKT strategies cannot yet be determined, the ongoing engagement and continued commitment of the advisory group to engage in all stages of the research process is in itself a positive impact. Members of the advisory group expressed their appreciation to the researchers for having the opportunity to work on

action-oriented research that aligns with their community needs and priorities. Future goals include evaluating community members' perceptions and use of the *Strengthening My Healing Journey* booklet, as well as facilitators and challenges to the IKT approach.

There were various opportunities for capacity building among graduate students and early career researchers starting to work with First Nations communities, as well as clinical staff in the community. These included research-skills improvement (e.g., learning about culturally safe and collaborative research methodologies) as well as discussions about research dissemination through conferences and future publications (e.g., co-authorship agreements).

Lessons learned include the amount of time it takes to establish trust and develop meaningful relationships with First Nations community members engaged in IKT. This project was built on positive engagement with the community that was developed during a previous project. Moreover, researchers should be aware that community priorities may change over the duration of a project, thereby influencing the direction of the research. Our First Nations partners shared their appreciation for the co-creation to enhance understanding of their traditional ways of knowing about wellness, healing and illness, which have long been ignored. Recognizing that research with First Nations communities requires partnerships that embrace authentic power sharing and co-production of knowledge, using an IKT approach was foundational for us to engage in this research. Our partnership allowed ongoing engagement in a program of research that aims to improve culturally safe care for Indigenous peoples in Canada. Acknowledging the socio-historical factors that profoundly affect Indigenous peoples' health, such as the ongoing impact of colonization, poverty and racism, is important for building open and trusting relationships with First Nations people. We found that being aware and knowledgeable of cultural dynamics is necessary to be responsive to both individual and community needs. However, the most compelling lesson learned was the importance of recognizing the resilience, pride and sense of humour that played prominent roles throughout our IKT collaboration.

REFERENCES

1. Canadian Partnership Against Cancer. Report on national forum on First Nations, Inuit and Metis cancer control. Toronto, ON: Canadian Partnership Against Cancer; 2009. Available from: https://s22457.pcdn.co/wp-content/uploads/2018/12/fnim_national_forum_2009_EN.pdf
2. Cancer Care Manitoba. Aboriginal cancer care progress report. Winnipeg, MB: Cancer Care Manitoba; 2008.
3. Health Council of Canada. The health status of Canada's First Nations, Inuit and Métis peoples. Toronto, ON: Health Council of Canada; 2005.
4. Canadian Partnership Against Cancer. First Nations cancer control in Canada baseline report. Toronto, ON: Canadian Partnership Against Cancer; 2013. Available from: https://www.partnershipagainstcancer.ca/wp-content/uploads/2017/12/first-nations-cancer-control-baseline-report.pdf
5. Akechi T, Okuyama T, Onishi J, Morita T, Furukawa TA. Psychotherapy for depression among incurable cancer patients. *Cochrane Database Syst Rev*. 2008;2:CD005537.
6. Applebaum AJ, Stein EM, Lord-Bessen J, Pessin H, Rosenfeld B, Breitbart W. Optimism, social support, and mental health outcomes in patients with advanced cancer. *Psychooncology*. 2014;23(3):299–306.
7. Cheifetz O, Park Dorsay J, Hladysh G, MacDermid J, Serediuk F, Woodhouse LJ. CanWell: meeting the psychosocial and exercise needs of cancer survivors by translating evidence into practice. *Psychooncology*. 2014;23(2):204–215.
8. Mishra SI, Scherer RW, Snyder C, Geigle PM, Berlanstein DR, Topaloglu O. Exercise interventions on health-related quality of life for

people with cancer during active treatment. *Cochrane Database Syst Rev*. 2012;8:CD008465.
9. Hammond C, Thomas R, Gifford W, Poudrier J, Hamilton R, Brooks C, et al. Cycles of silence: First Nations women overcoming social and historical barriers in supportive cancer care. *Psychooncology*. 2017;26(2):191–198.
10. Poudrier J, Thomas-MacLean R. "We've fallen into the cracks": a photovoice project with Aboriginal breast cancer survivors. *Nurs Inq*. 2009;16(4):306–317.

Dialogue as a catalyst for equity-centred research: The Canadian Coalition for Global Health Research's Gathering Perspectives studies

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Keywords: dialogue; global health research; engagement; equity; integrated knowledge translation

BACKGROUND

This case is a story about the Canadian Coalition for Global Health Research's (CCGHR) leadership in the global health research community. Our integrated knowledge translation (IKT) story began when the CCGHR Policy & Advocacy Program* responded to a call from its members, initiating a series of studies grounded in cycles of generating and synthesizing evidence, and engaging and responding to people involved in using, doing or supporting global health research. In these studies, the research team, participants and target audiences were from the same community and connected through a shared interest in global health research. Each of these groups shaped the entire research process, from problem definition through to study design, analysis and dissemination, thereby making this series of studies a responsive program of research characterized by an IKT approach.

Global health inequities, and the research to inform related responses, were at the foundation of the present study. There is strong evidence about the causes and distribution of unfair differences in health outcomes and life expectancy within and between countries.[1-4] Where you are born determines the quality and length of your life, not because of geography but because of unfair advantages and disadvantages in the global distribution of power, wealth and resources.[5] Research plays an important role in generating responsive solutions to advance health equity.[6,7] However, there are important questions about the ways in which global health research actually contributes to health equity, including how research practices can contribute to challenging (rather than reinforcing) the root causes of inequities.[8-10] The present studies were born from critical questions about the role of research in global health.

In 2012, the CCGHR Policy Influence Program met with the CCGHR University Advisory Council† to discuss a national report about Canada's contributions to global health.[11] After exploring how equity and research were and were not reflected in the report, council members tasked the Policy Influence Program leaders with a major undertaking: open an international dialogue about what the future for global health research in Canada *should* be.

* The CCGHR is a network of people, including researchers, policy-makers, practitioners, and others across Canada and around the world who share a common interest in using research to strengthen health systems and contribute to achieving health equity worldwide. For more information, visit www.ccghr.ca.

† This council comprises representatives from each of the 29 institutional CCGHR members. It is part of the CCGHR network structure that also includes a Student and Young Professional Network; general membership (~400 individuals); three program areas; and the CCGHR Board and Secretariat.

DESCRIPTION OF IKT ACTIVITIES

Overall, these studies were guided by the knowledge-to-action cycle.[12] We also drew upon principles of appreciative inquiry,[13] the reflexive and transformative spirit of critical pedagogies[14,15] and relational practices.[16,17] We invited perspectives from a diverse and dispersed community. Not only were there wide geographic divides between the people involved in global health research, but there were also differences in the motivations, interests, values and beliefs underlying their involvement. In an effort to create an open forum where we could honour this diversity while inviting collective reflection about aspirational ideals, we chose deliberative dialogue as our central method.

Deliberative dialogue is a relational research and knowledge translation method for bringing people together to cooperatively discuss a possible future, informed by what is known (i.e., synthesis of research evidence and other sources of knowledge) about something of importance to a community.[18,19] Distinct from methods that 'extract' data from participants, this method emphasizes developing mutual understanding and shared interpretations of the *implications and contextualized meanings* of synthesized evidence.[16] Following in-depth stakeholder analysis[20] considering possible perspectives and individuals' capacities to engage with others, we invited students, researchers, funders, policy-makers, administrators and practitioners who self-identified as being 'involved' in global health research‡ to participate in a series of deliberative dialogues. We intentionally sought diversity in perspectives to ensure representation from across a spectrum of involvement and positioning in global health research. Overall, 18 dialogues including more than 350 people were held across Canada and complemented by a series of online open forums accessed by people around the world.

In the first series of dialogues held between May and November 2013, we generated collective insights about foundational values guiding how we, as people with this shared interest in global health research, *should* engage in our field.[21,22] Further, we invited participants to identify strategic opportunities for action, which culminated in three important calls for action: assess and respond to the dynamic funding landscape; elaborate a set of guiding standards for practice in our field; and actively disseminate the results of the study with tailored products for key audiences (e.g., universities, researchers, teachers and students, non-government organizations, elected officials and policy-makers).

We responded to these calls for action through a second series of dialogues held between April 2014 and March 2016. After each deliberative dialogue, we integrated new information with previous dialogues. This second series served to evolve the now widely-used CCGHR Principles for Global Health Research§.[23,24] After each series, data analysis and synthesis were guided by a framework** developed in response to the unique challenges posed by dialogic data.[25] We took time to reconnect with the University Advisory Council, the CCGHR Board and general membership, and others (e.g., funding agencies, senior researchers, partners from outside of Canada, participants at key conferences) to seek their advice about:

‡ We broadly defined 'involvement' in global health research, including a range of activities from teaching to mentoring, doing, using, partnering or supporting.

§ For a video overview of the principles, visit https://www.youtube.com/watch?v=60dYVK_NaVE. Additional materials are also available at www.ccghr.ca.

** This framework involves complementary cycles of engagement and synthesis, driven by a balance of qualitative analysis strategies (categorizing and connecting) and interpretive lenses (suspicious and empathetic). For more detail and a visual of the framework, see Plamondon, Bottorff & Cole (2015) referenced below.[25]

(a) what we had learned and what we were proposing; and (b) what kinds of knowledge products they believed would be most useful. Through these feedback loops we were able to identify new target audiences for knowledge translation, including, for example, elected officials who may be in positions to guide policy related to global health research.

IMPACT AND IMPLICATIONS

Because the questions and calls for action came from the CCGHR University Advisory Council, potential research users directed this research, including the problem, questions, study design, data analysis, interpretation, and the prioritization and creation of knowledge translation products. As a result, the studies strongly resonated with people involved in global health research. The CCGHR Principles for Global Health Research in particular are being used extensively in Canada and abroad. They have served as a foundation for graduate courses or research, guided training for peer review of scholarly work and informed national funding policy.[26,27] Because the relational approach focused on building mutual understanding and collective articulation of shared values and vision, the process and outcomes resonate with people broadly interested in health equity. Thanks to this process, our team focused on developing user-driven knowledge translation products (e.g., a video, learning guide and training institutes) before pursuing traditional academic outputs. The ultimate products are widely looked to by both CCGHR members and others involved in global health research to advocate for equity-centred investment, practices and partnerships. Using an IKT approach to shape this program of research, particularly the sequential use of deliberative dialogue, was pivotal to facilitating impact.

The use of a relational knowledge translation strategy as a research method was innovative and effective. These sequential dialogue methods were energizing for participants and enabled networking beyond the formal membership of the CCGHR. Further, we have maintained a strong responsive relationship between the CCGHR and its members. With a frugal budget, we leaned heavily on both the volunteer efforts of research team members and the generosity of participants offering their time and energy. This was only possible because everyone involved, from the research team to participants to knowledge users, were incredibly passionate and dedicated. An important lesson we can offer is a simple note of caution about the potential resources required to make a series of deliberative dialogues possible. We believe this was successful because the studies were deeply aligned with the needs and interests of the participants. Moreover, the study questions, calls for actions and subsequent responsive studies were all driven by the same groups of people. This a promising example for other geographically or otherwise dispersed communities that share a strong, future-focused interest.

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REFERENCES

1. Donkin A, Goldblatt P, Allen J, Nathanson V, Marmot M. Global action on the social determinants of health. *BMJ Glob Health*. 2017;3(Suppl 1):e000603.
2. Marmot M, Allen J, Bell R, Bloomer E, Goldblatt P. WHO European review of social determinants of health and the health divide. *Lancet*. 2012;380(9846):1011–1029.

3. Ottersen OP, Dasgupta J, Blouin C, Buss P, Chongsuvivatwong V, Frenk J, et al. The political origins of health inequity: prospects for change. *Lancet*. 2014;383(9917):630–667.
4. McNeill D, Birkbeck CD, Fukuda-Parr S, Grover A, Schrecker T, Stuckler D. Political origins of health inequities: trade and investment agreements. *Lancet*. 2016;389(10070):760–762.
5. WHO Commission on Social Determinants of Health. Closing the gap in a generation: health equity through action on the social determinants of health. Geneva, Switzerland: WHO; 2008. Available from: http://www.who.int/social_determinants/final_report/csdh_finalreport_2008.pdf
6. Global Ministerial Forum for Research on Health. Bamako call to action on research for health: strengthening research for health, development, and equity. Bamako, Mali; 2008.
7. World Health Organization. Rio Political Declaration on Social Determinants of Health. Rio de Janeiro, Brazil; 2011.
8. Crane JT. Unequal 'partners.' AIDS, academia, and the rise of global health. *Behemoth*. 2010;3(3):78–97.
9. Benatar S, Upshur R, Gill S. Understanding the relationship between ethics, neoliberalism and power as a step towards improving the health of people and our planet. *The Anthropocene Review*. 2018;5(2):155–176.
10. Brisbois BW, Spiegel JM, Harris L. Health, environment and colonial legacies: situating the science of pesticides, bananas and bodies in Ecuador. *Soc Sci Med*. 2019;239:112529.
11. Canadian Academy of Health Sciences (CAHS). Canadians making a difference: the expert panel on Canada's strategic role in global health. Ottawa, ON: CAHS; 2011.
12. Graham ID, Logan J, Harrison MB, Straus SE, Tetroe J, Caswell W, et al. Lost in knowledge translation: time for a map? *J Contin Educ Health Prof*. 2006;26(1):13–24.
13. Ludema CJD, Fry RE. The practice of appreciative inquiry. In: Reason P, Bradbury H, eds. *The SAGE Handbook of Action Research*. 2nd ed. London: SAGE; 2008. p. 280–297.
14. Shor I, Freire P. What is the “dialogical method" of teaching? *J Educ*. 1987;169(3):11–31.
15. Freire P. *Pedagogy of the Oppressed*. New York: Continuum; 1997.
16. Plamondon K, Caxaj CS. Toward relational practices for enabling knowledge-to-action in health systems: the example of deliberative dialogue. *ANS Adv Nurs Sci*. 2018;41(1):18-29.
17. Gergen KJ. *Relational Being: Beyond self and community*. Oxford; Oxford University Press; 2009.
18. Boyko JA, Lavis JN, Abelson J, Dobbins M, Carter N. Deliberative dialogues as a mechanism for knowledge translation and exchange in health systems decision-making. *Soc Sci Med*. 2012;75(11):1938-1945.
19. Plamondon K. An introduction to deliberative dialogue. Kelowna, BC; 2017. Available from: https://www.youtube.com/watch?v=D3CPd_nRcX0
20. Campbell S. Knowledge translation curriculum. Ottawa, ON: Canadian Coalition for Global Health Research; 2012.
21. Canadian Coalition for Global Health Research. Gathering Perspectives: a call for dialogue on the role of research in a Canadian vision for global health. Ottawa, ON: Canadian Coalition for Global Health Research; 2013. Available from: http://www.ccghr.ca/wp-content/uploads/2013/05/CCGHR_Gathering_Perspectives_2013.pdf
22. Canadian Coalition for Global Health Research. Gathering Perspectives: dialogue on the role of research in a Canadian vision for global health, fall 2013 dialogue snapshot. Ottawa, ON: Canadian Coalition for Global Health Research; 2013. Available from: https://www.ccghr.ca/wp-content/uploads/2013/11/Gathering-Perspectives-Fall-2013-Dialogue-Snapshot_Revised.pdf
23. Canadian Coalition for Global Health Research. CCGHR Principles for Global Health Research. Ottawa, ON: Canadian Coalition for Global Health Research; 2015. Available from: http://www.ccghr.ca/resources/principles-global-health-research/
24. Plamondon KM, Bisung E. The CCGHR Principles for Global Health Research: centering equity in research, knowledge translation, and practice. *Soc Sci Med*. 2019;239:112530.

25. Plamondon KM, Bottorff JL, Cole DC. Analyzing data generated through deliberative dialogue: bringing knowledge translation into qualitative analysis. *Qual Health Res*. 2015;25(11):1529–1539.
26. Canadian Institutes of Health Research. Institute of Population & Public Health strategic research priorities. Ottawa, ON; 2011.
27. Canadian Coalition for Global Health Research. Report on external consultations for CIHR/IDRC strategic plan. Ottawa, ON; 2018.

Ready to go: Using an integrated knowledge translation approach to support the development of a funding application to explore patient engagement in Canadian circulatory and respiratory diseases research

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Keywords: patient engagement; circulatory; respiratory; grant application; integrated knowledge translation

BACKGROUND

Circulatory and respiratory diseases are a major cause of morbidity and mortality worldwide and account for significant health-care expenditure.[1] In concert with the burgeoning rates of chronic disease and rapid population ageing, circulatory and respiratory diseases are expected to rise sharply over the coming decades.[2-4] In response, health-care organizations are increasingly challenged to develop and implement evidence-informed services to address gaps and variations in practice and improve health outcomes.[5-13] Meaningfully engaging with patients is increasingly seen as a way to improve the relevance and impact of research.[14]

While the concept of involving patients and knowledge users in research is well-established across many disciplines, strategically engaging patients to guide research, including its focus and outcomes, represents a new research frontier.[15] This case study illustrates the use of an integrated knowledge translation (IKT) approach[16] to foster early partnerships between researchers and knowledge users to support the development of a grant proposal.

Patient engagement in circulatory and respiratory diseases research

Meaningfully engaging patients and including patient-reported outcomes and priorities are hailed as mechanisms to bridge research-practice gaps and develop evidence-based services that improve patient outcomes.[15-17] The Canadian Institutes of Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR) highlights that researchers must create a "strong foundation" for meaningful patient engagement.[18,19] This can include a full spectrum of engagement activities, from involving patients for their experiential insights, to fully collaborative partnerships that support knowledge co-creation and empowered decision-making. While there has been a recent surge in interest in patient engagement, there is great variation in how this occurs and little evidence to support its impact.[20,21]

The focus of this research was to examine patient engagement in circulatory and respiratory disease research and to identify gaps, priorities and opportunities for future patient-oriented research. To get started, we recognized the need for early engagement between researchers and knowledge users, including patients. Our early connections

with patient partners occurred through existing research relationships, while new collaborations with other knowledge users occurred through key national circulatory and respiratory research networks. Additionally, we reached out to patient engagement and IKT leaders. Despite early success with engagement, we recognized that we needed to secure financial support to allow us to continue to build further collaborations, enable collection of preliminary data, and provide resources to support ongoing team building and grant development.

DESCRIPTION OF IKT ACTIVITIES

IKT research requires early and sustained collaboration between researchers and knowledge users throughout the research process.[16] To achieve this, we first worked to build the collaborations needed to allow us to begin to shape and plan the initial research. To do this, team members undertook in-person and teleconference meetings with research scientists and knowledge users, including network leaders and patients, to facilitate knowledge exchange, identify opportunities for collaboration, determine potential roles and contributions, and establish collective goals and interests. We first leveraged our existing connections to allow for the early exploration of this work and then sought to widen our engagement activities based on the recommendations garnered from our initial connections. Meeting notes were collated to identify shared interests and document potential research questions and deliverables. These were distributed to team members to stimulate ongoing discussion and solicit input into our planning activities. Approximately 20 meetings occurred during this early stage, with two meetings planned to specifically examine opportunities for research funding.

Through these early discussions our team determined that an inter-network meeting, in addition to gathering primary data on experiences of patient-oriented research, would best enable the development of further research and provide valuable data for the partnering networks. However, without access to early funding, we recognized that we may be unable to gain sufficient momentum or may fail in our mission altogether. As a result, we determined that a CIHR Planning and Dissemination Grant would provide the support needed and worked collectively to develop a research proposal.

We believe our early success was the result of two factors. First, by adopting an inclusive approach, we were able to rapidly bring together a diverse group of collaborators to assist us to understand patient engagement and its complexity within the context of circulatory and respiratory diseases research. We were then able to provide opportunities for team members to contribute to the research planning and subsequent funding application. Second, we adopted the principles of patient engagement by facilitating inclusiveness, support, mutual respect and a commitment to the co-creation of knowledge.[18] As a result, patient partners were engaged as authors, co-applicants and contributors at all stages of the work, and were provided compensation, training and support in order to optimize meaningful engagement.

IMPACT AND IMPLICATIONS

The adoption of an IKT approach provided a solid foundation for our research and led to the development of two successful grant proposals. Engaging the right stakeholders from the outset of the project was a key factor in our success. Through these early activities we were able to identify driving questions and forge momentum to foster the development of a funding proposal. We were also opportunistic and identified the planning grant competition as a possible funding avenue, despite tight timelines. By being agile, we were able to mobilize rapidly to facilitate proposal development and cement a commitment to further collaborative research. While the initial grant

provided modest funding, it significantly impacted our ability to further build our team and foster larger-scale research.

The experience of initiating an IKT process also provided valuable learning opportunities. First, our team worked best when there was regular communication, including access to written summaries. This was particularly important for the research scientists and network leaders, whose busy schedules often prohibited lengthy meetings. Second, providing clear guidance around expectations and timelines was important and facilitated greater clarity and trust. Finally, there was considerable variation in patient engagement across the networks. Our inclusive approach created a safe space to examine drivers and barriers of effective patient engagement.

CONCLUSION

This case study is an example of an IKT process that fostered robust collaborations with researchers and knowledge users, including patients, and led to the development of an international program of research aimed at optimizing supports for patient engagement and patient-oriented research. The use of an IKT approach was beneficial as it: (1) provided a framework to foster collaborative and meaningful partnerships; (2) allowed for inclusion of diverse knowledge users throughout the research process; and (3) facilitated the development of research that can respond to real-world needs and issues. In 2017, we were successfully funded to undertake our initial research exploring patient engagement in circulatory and respiratory health research networks. In 2019, further operating funds were awarded to support a larger program of research exploring organizational capacity for patient engagement within health research networks in Canada and the United Kingdom. We hope that this research will advance the science of patient engagement and improve the development and uptake of evidence that is responsive to the needs, values, and priorities of patients and the public.

REFERENCES

1. Mendis S, Puska P, Norrving B, eds. Global atlas on cardiovascular disease prevention and control. Geneva, Switzerland: World Health Organization; 2011.
2. Heidenreich PA, Trogdon JG, Khavjou OA, Butler J, Dracup K, Ezekowitz MD, et al. Forecasting the future of cardiovascular disease in the United States: a policy statement from the American Heart Association. *Circulation*. 2011;123(8):933-944.
3. Mannino DM, Buist AS. Global burden of COPD: risk factors, prevalence, and future trends. *Lancet.* 2007;370(9589):765-773.
4. Broemeling AM, Watson DE, Prebtani F. Population patterns of chronic health conditions, co-morbidity and healthcare use in Canada: implications for policy and practice. *Healthc Q*. 2008;11(3):70–76.
5. Gifford WA, Graham ID, Davies BL. Multi-level barriers analysis to promote guideline based nursing care: a leadership strategy from home health care. *J Nurs Manag*. 2013;21(5):762–770.
6. Banner D, Janke F, King-Shier K. Making evidence-based practice happen in 'real world' contexts: the importance of collaborative partnerships. In: Lipscom M, ed. *Exploring evidence-based practice: Debates and challenges in nursing*. 1st ed. London: Routledge; 2015. p. 11-28.
7. Wennberg J. Time to tackle unwarranted variations in practice. *BMJ*. 2011;342(7799):687–690.
8. Ramanujam R, Rousseau DM. The challenges are organizational not just clinical. *J Organ Behav*. 2006;27(7):811–827.
9. Allard J, Durand C, Anthony SJ, Dumez V, Hartell D, Hébert M-J, et al. Perspectives of patients, caregivers and researchers on research priorities in donation and transplantation in Canada: a pilot workshop. *Transplant Direct*. 2017;3(2):e127.
10. Nass P, Levine S, Yancy C. Methods for involving patients in topic generation for patient-centered comparative effectiveness research: an international perspective. Washington, DC:

Patient-Centered Outcomes Research Institute (PCORI); 2012.
11. Wagner EH, Austin BT, Davis C, Hindmarsh M, Schaefer J, Bonomi A. Improving chronic illness care: translating evidence into action. *Health Aff*. 2001;20(6):64-78.
12. Chobanian AV, Bakris GL, Black HR, Cushman WC, Green LA, Izzo JL, et al. The seventh report of the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure. *JAMA*. 2003;289(19):2560-2572.
13. Asch SM, Kerr EA, Keesey J, Adams JL, Setodji CM, Malik S, et al. Who is at greatest risk for receiving poor-quality health care? *N Engl J Med*. 2006;354(11):1147-1156.
14. Banner D, Bains M, Carroll S, Kandola DK, Rolfe DE, Wong C, et al. Patient and public engagement in integrated knowledge translation research: are we there yet? *Res Involv Engagem*. 2019;5:8.
15. Sacristán JA. Patient-centered medicine and patient-oriented research: Improving health outcomes for individual patients. *BMC Med Inform Decis Mak*. 2013;13:6.
16. Graham ID, Logan J, Harrison MB, Straus SE, Tetroe J, Caswell W, et al. Lost in knowledge translation: time for a map? *J Contin Educ Health Prof*. 2006;26(1):13-24.
17. Karazivan P, Dumez V, Flora L, Pomey MP, Del Grande C, Ghadiri DP, et al. The patient-as-partner approach in health care: a conceptual framework for a necessary transition. *Acad Med*. 2015;90(4):437-441.
18. Canadian Institutes of Health Research. Strategy for patient-oriented research: Patient engagement framework. Ottawa, ON: CIHR. 2014.
19. Canadian Institutes of Health Research. Canada's strategy for patient-oriented research: Improving health outcomes through evidence-informed care. Ottawa, ON: CIHR. 2011.
20. Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, et al. Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expect*. 2014;17(5);637-650.
21. Mockford C, Staniszewska S, Griffiths F, Herron-Marx S. The impact of patient and public involvement on UK NHS health care: a systematic review. *Int J Qual Health Care*. 2012;24(1):28-38.

The Attachment and Child Health (ATTACH) integrated knowledge translation project

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Keywords: attachment; reflective function; community intervention; high-risk families; integrated knowledge translation

BACKGROUND

Over the last 10 years, the Palix Foundation, via the Alberta Family Wellness Initiative (AFWI), has worked to raise and spread awareness of synthesized neuroscientific evidence of the importance of early experiences for healthy brain development, called the "core story of brain development" or the Brain Story. To this end, AFWI helped fund a Research Chair in Parent-Infant Mental Health, which is held by the first author, Nicole Letourneau, at the University of Calgary. AFWI also fostered connections between the chair and the Calgary Urban Project Society - an inner-city service agency focused on housing, education and health services for the city's most vulnerable families and children. The agency's executive director, Carlene Donnelly, together with her staff (e.g., clinicians, policy advisors) and Letourneau, worked to mobilize findings from the Brain Story to create the Attachment and Child Health (ATTACH) project. While the implementation and evaluation of ATTACH undertaken at Calgary Urban Project Society is now complete, agency staff continue to independently deliver the program.

In the Brain Story, exposure to "toxic stressors," including parental violence, depression and addictions, negatively impact child development because these stressors reduce parental sensitivity and responsiveness to children.[1] Reduced sensitivity and responsiveness interfere with forming the secure parent-child attachments necessary for healthy child development.[2,3] Secure attachment is influenced by parental reflective function, defined as the capacity for insight into both one's own and one's child's thoughts and feelings. This insight enables the parent to regulate their feelings and behaviour toward their child.[4,5] Few reflective function interventions exist, and those that do typically focus on mothers' understanding of their own psychological caregiving representations, that is, how one's own attachment history impacts parenting behaviour today. As such, existing interventions do not promote learning reflective function skills via practice and ignore co-parents, including fathers or other important family caregivers.[6]

Letourneau, Donnelly and Donnelly's team became interested in programming to address reflective function and attachment as early as 2013. In particular, the team learned of the importance of these unaddressed areas (i.e., the need for practice of reflective function skills and inclusion of co-parents) for high-risk families through a series of AFWI symposia. Building on this research and a desire to promote innovation relevant to the Brain Story within community practice, they developed and pilot-tested a reflective function intervention for at-risk mothers

and co-parents affected by violence, depression and addictions. Letourneau and Hart developed the program and sought input and feedback from Calgary Urban Project Society leadership and staff through a series of in-person and telephone meetings. The ATTACH team sought to improve the likelihood of increased parental sensitivity and responsiveness through improved parental reflective function, with the ultimate aim of promoting secure maternal-infant attachment and child development.

Funding was obtained from multiple sources, including the Palix Foundation Accelerating Innovation program, PolicyWise's Frontiers of Innovation program, the University of Calgary's Eyes High Post-Doctoral program and University of Calgary Seed Funding.

DESCRIPTION OF IKT ACTIVITIES

Fostered by connections established within the context of AFWI, the project utilized community-based participatory[7,8] and integrated knowledge translation (IKT)[9] approaches that involved members of working and advisory groups as partners.[10] It should be noted that in Alberta, AFWI had undertaken considerable effort to educate health and social service professionals, researchers, government officials and the public about the Brain Story, which included content on concepts relevant to reflective function and attachment (e.g., sensitivity and responsiveness as "serve and return"). Thus, in seeking to undertake IKT the ATTACH team found that we all spoke the same language and cared about the same issues impacting high-risk young families in our community. Further, having Donnelly as a champion at the Calgary Urban Project Society facilitated connections with staff and other agency leaders. Telephone calls and email contacts were replied to and plans easily made for the consultations necessary to ensure the program met agency and client needs. Thus, consultations occurred in both structured (e.g., all-staff workshops/presentations, formal meetings with agency leaders and responsible front-line staff) and unstructured ways (e.g., emails, telephone calls, hall conversations). For example, details regarding the length of sessions, importance of organized childcare for parents, honouraria amounts and connections with clients' case managers were determined through partner discussions. Specific feedback, such as ensuring that materials were gender neutral and diverse, would not have been incorporated without the advice of partners. Moreover, regular meetings (three times per year) between university researchers and community service providers ensured that progress, plans and insights were regularly shared among the team members. A wider community of stakeholders from research, policy and practice were also invited to receive a regular newsletter (two times per year) to inform them of the progress of ATTACH and maintain two-way communication channels.

IMPACT AND IMPLICATIONS

As a result of the work at the Calgary Urban Project Society, two additional sites for pilot testing were identified, with focus given to women who were in a shelter setting, having fled domestic violence. The program was ultimately implemented at Calgary Urban Project Society and two additional agencies, which are either still delivering the program independently (2/3 of the agencies, including Calgary Urban Project Society) or planning to do so.

The primary benefits of the IKT approach are twofold. First, engagement from the outset promoted a sense of ownership at Calgary Urban Project Society, as evidenced by continued delivery of the program and intention to train more staff. Second, Calgary Urban Project Society partners became respected advocates for the program, promoting scaling and spread to other agencies in Calgary. This effect has in fact snowballed, with more than 10 agencies across

Canada reaching out to inquire about training and scaling. In summary, engaging with community partners from the outset about a shared desire to develop programming that better meets the needs of clientele is an exciting and rewarding adventure. Building programs together promotes a sense of ownership that ensures that partners become the best advocates for the program, helping scale and spread effective programs.

REFERENCES

1. Center on the Developing Child at Harvard University. *The foundations of lifelong health are built in early childhood*. Boston, MA: Harvard University; 2010.
2. Ainsworth M, Blehar M, Waters B, Wall S. *Patterns of attachment: a psychological study of the strange situation*. Hillsdale, NJ: Lawrence Erlbaum Associates; 1978.
3. Lamb ME, Thompson RA, Gardner W, Charnov EL, eds. *Infant-mother attachment: the origins and developmental significance of individual differences in Strange Situation behavior*. New York, NY: Routledge; 2013.
4. Steele H, Steele M, Fonagy P. Associations among attachment classifications of mothers, fathers, and their infants. *Child Dev*. 1996;67(2):541-555.
5. Ames EW, Bradley CF. Infant and parent characteristics related to parental reports of colic in one-month-old and three-month-old infants. Paper presented at: *Canadian Psychological Association Meeting*; 1983; Winnipeg, MB.
6. Letourneau N, Tryphonopoulos P, Giesbrecht G, Dennis CL, Bhogal S, Watson B. Narrative and meta-analytic review of interventions aiming to improve maternal-child attachment security. *Infant Ment Health J*. 2015;36(4):366-387.
7. Shallwani S, Mohammed S. Community-based participatory research: a training manual for community-based researchers. Toronto, ON: University of Toronto; 2007.
8. Hartwig K, Calleson D, Williams M. Community-based participatory research - getting grounded. In: The Examining Community-Institutional Partnerships for Prevention Research Group. *Developing and sustaining community-based partnerships: A skill-building curriculum*. 2006:11-33.
9. Straus S, Tetroe J, Graham ID, eds. *Knowledge translation in health care: moving from evidence to practice*. 2nd ed. West Sussex: John Wiley & Sons; 2013.
10. Alberta SPOR SUPPORT Unit, Patient Engagement Platform. Patient engagement in health research: a how-to guide for researchers (version 8.0).

Using an integrated knowledge translation approach to better understand the impacts of adverse childhood experiences among adult primary care patients: The EmbrACE Study

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BACKGROUND

Approximately seven in 10 primary care patients in Alberta report a history of adverse childhood experiences (ACEs), such as childhood abuse, neglect and household dysfunction.[1] ACEs have been repeatedly identified as risk factors for a range of health problems in adulthood, including increased chronic disease, mental illness, health-risk behaviours and rates of health-care utilization.[2-5] Despite wide recognition of ACEs as determinants of poor health in adulthood, ACEs are not routinely addressed within primary care settings. This represents a significant failure to integrate empirical research into clinical practice and health-care decision-making. To address this problem, the EmbrACE Study (formerly the ACEs-Alberta Study) was developed.

The EmbrACE Study was established in 2013 and utilizes a multi-phased, integrated knowledge translation (IKT) approach to enhance clinical care and health outcomes for adult primary care patients who report a history of ACEs. The EmbrACE Study is funded by the Palix Foundation, a private foundation that supports knowledge mobilization and applied research into the science of early brain development and its impact on lifelong health. Together, the EmbrACE research team and the Palix Foundation have conducted research designed to complement and build on existing trauma-informed policies, programs and practice within primary care settings in Calgary, Alberta.

The primary objectives of the EmbrACE Study are: (1) to identify a clinically validated tool to measure patient ACE history (Phase 1, completed 2014); (2) to evaluate the associations between ACEs and health outcomes, such as chronic disease and mental illness, among diverse samples of primary care patients (Phase 2, completed 2016); and (3) to develop and test a clinical treatment program aimed to improve health outcomes among primary care patients with a history of ACEs (Phase 3, completed 2019).

DESCRIPTION OF IKT ACTIVITIES

Integrated knowledge translation, defined as the engagement of knowledge users (i.e., patients, health-care providers and policy-makers) as active participants in the research process has been critical to the mandate and success of the EmbrACE Study. Each phase of the EmbrACE Study has been completed within primary care settings, and the integration of the study within Alberta primary care networks allows for direct contact with knowledge users and, ultimately, allowed for the development and delivery of a clinical treatment protocol for patients with a history of ACEs.

The EmbrACE Study research team consists of approximately 15 health professionals, including health researchers, physicians, psychologists, policy-makers, trainees and health-care administrators (e.g., executive directors of local primary care networks). The research team meets monthly to discuss the key priorities and progress of the study, develop research questions, interpret findings, and discuss relevant theoretical and empirical literature. Critically, the research team also includes a group of primary care patients who play an active role in the development, implementation and evaluation of each phase of the EmbrACE Study.

Patient members of the EmbrACE Study research team were recruited from primary care settings at the start of the study and represent a range of lived experiences of ACEs and current health conditions. Approximately three times per year, one of the research team members (often a trainee) facilitates a focus group meeting specifically to elicit insights from patients regarding how ACEs have influenced their health, their experiences within health-care settings and their reactions to EmbrACE Study materials (e.g., questionnaires, recruitment materials, draft treatment protocols). Patient members are also invited to attend the monthly EmbrACE research team meetings, where they provide insights on matters such as the identification of research questions, study methodology and data interpretation.

Patient members also played an integral role in the development and implementation of the EmbrACE clinical treatment program (Phase 3). All patient members reviewed the treatment protocols prior to the open trial. Furthermore, several members participated in the open trial and provided researchers with subsequent feedback regarding their experiences in the treatment program. For instance, patient members provided valuable insight regarding the use of language (e.g., treatment "program" versus "intervention"), the decision to utilize group therapy rather than individual therapy and the time dedicated to various areas of treatment content. Finally, patient members play a critical role in knowledge dissemination. For instance, several EmbrACE Study presentations at national and international conferences have included impactful live or video presentations from patients.

The partnership between the EmbrACE Study and the Palix Foundation was a key enabler of our ability to engage in IKT. Between 2010 and 2012, several members of the EmbrACE research team were invited to participate in a Palix knowledge mobilization initiative. The goals of the initiative were to: (1) deepen understanding of the role of brain development and ACEs on future outcomes across a range of professionals in policy and practice, from health, education, justice and human services; (2) encourage interdisciplinary dialogue, networks and collaboration; and (3) support the development and implementation of projects that could embed the knowledge at multiple system levels. To launch the EmbrACE Study, Palix partnered with the EmbrACE research team by providing staff support in developing the proposal and committed funding for all phases of the project. A Palix staff member continues to sit on the EmbrACE research team and actively supports the work.

In addition, the EmbrACE Study has generated forums for ACE-related learning, which support the partnerships that allow for IKT. For instance, in 2014, the EmbrACE research team worked closely with the Palix Foundation to organize and implement a scientific conference in Calgary on the effects of ACEs. Over 300 health professionals and policy-makers attended the conference, which showcased presentations from the EmbrACE research team and internationally recognized experts. More recently, members of the EmbrACE Study hosted a formal luncheon,

wherein stakeholders, patients and health professionals were invited to learn about and discuss the study's latest findings.

Between 2010 and 2014, Palix hosted two additional knowledge mobilization strategies with similar objectives, producing 400 additional "change agents" who are embedded in systems and services across the province. This has helped create a productive environment in which to conduct applied ACE research in Alberta. Through its advocacy efforts and networks, Palix also plays an active role in disseminating the research findings and supports additional, complementary projects that will help firmly entrench ACE science across multiple service settings for the benefit of all Albertans.

IMPACT AND IMPLICATIONS

A primary goal of the EmbrACE Study is to increase knowledge and awareness regarding the impact of ACEs on adult health outcomes. Study results have: (1) provided health-care professionals with a clinically validated tool to measure patient ACEs; (2) highlighted the pervasiveness of ACEs among Albertan primary care patients; and (3) demonstrated the significant impact of ACEs on adult health status.[1,6-8]

Involving knowledge users within each phase of the study has enabled EmbrACE Study researchers to: (1) effectively incorporate patient experience to ensure a patient-focused screening-and-intervention model of care; and (2) better understand the realities of the environment and systems in which the research results would be implemented (i.e., primary care settings). As the study has evolved, several lessons were learned about engaging knowledge users in the research process. For instance, while involving knowledge users facilitated rich discussion and enabled us to consider diverse perspectives, it could, at times, also serve as a challenge to decision-making in large group meetings. To address this issue, we have found the development of working groups to be helpful. Additionally, we have learned it is important to clearly define roles (including leadership and facilitator roles), action items and time commitments for group members between meetings.

REFERENCES

1. Poole JC, Dobson KS, Pusch D. Childhood adversity and adult depression: the protective role of psychological resilience. *Child Abuse Negl.* 2017;64:89-100.
2. Anda RF, Brown DW, Dube SR, Bremner JD, Felitti VJ, Giles WH. Adverse childhood experiences and chronic obstructive pulmonary disease in adults. *Am J Prev Med*. 2008;34(5):396-403.
3. Bonomi AE, Anderson ML, Rivara FP, Cannon EA, Fishman PA, Carrell D, Thompson RS. Health care utilization and costs associated with childhood abuse. *J Gen Intern Med*. 2008;23(3):294-299.
4. Dong M, Giles WH, Felitti VJ, Dube SR, Williams JE, Chapman DP, et al. Insights into causal pathways for ischemic heart disease: adverse childhood experiences study. *Circulation*. 2004;110(13):1761-1766.
5. Dube SR, Miller JW, Brown DW, Giles WH, Felitti VJ, Dong M, et al. Adverse childhood experiences and the association with ever using alcohol and initiating alcohol use during adolescence. *J Adolesc Health*. 2006;38(4):444-e1-10.
6. Frampton NMA, Poole JC, Dobson KS, Pusch D. The effects of adult depression on the recollection of adverse childhood experiences. *Child Abuse & Negl.* 2018; 86:45-54.
7. Poole JC, Dobson KS, Pusch D. Anxiety among adults with a history of childhood adversity: psychological resilience moderates the indirect effect of emotion dysregulation. *J Affect Disord.* 2017;217:144-152.
8. Poole JC, Dobson KS, Pusch D. Do adverse childhood experiences predict adult interpersonal difficulties? The role of emotion dysregulation. *Child Abuse Negl*. 2018;80:123-133.


IKT
Research Network