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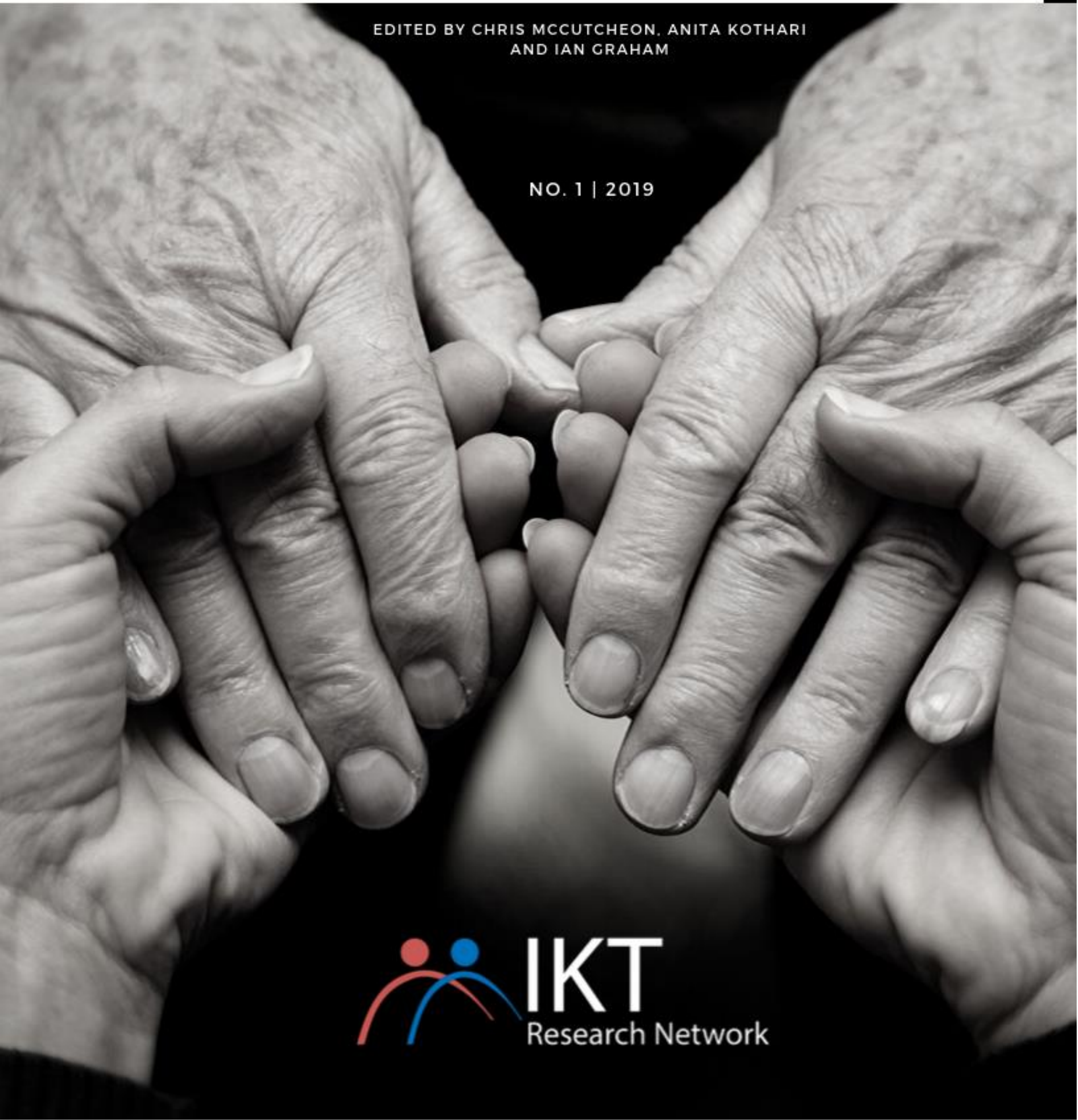
THE INTEGRATED KNOWLEDGE TRANSLATION RESEARCH NETWORK CASEBOOK



EDITED BY CHRIS MCCUTCHEON, ANITA KOTHARI
AND IAN GRAHAM

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In Memory of Paula Goering

In May 2016, we lost a dear colleague and a great champion and pioneer in integrated knowledge translation (IKT)**.** Dr. Paula Nina Goering was a leading Canadian health services researcher and nurse. Her 1985 PhD, a longitudinal study of community case management for people with serious mental illness, began her life-long commitment to producing evidence to improve our healthcare system. Paula was constantly in search of ways to support the most vulnerable to achieve a better quality of life. Her thinking was always innovative, out of the box, a ‘new slant on an old issue’.

Many of us remember the formidable policy partners that Paula worked with. While her charm, deep conviction and clear thinking were enough to engage many collaborators, it was her characteristic gentle but relentless persistence that brought even the most intractable of partners on board.

Paula’s crowning achievement may be the national *Housing First/Chez Soi* study, which influenced housing policy in Canada, both federally and provincially, and went on to receive international attention. However, numerous other examples of her impact come to mind. Her provincial level-of-care studies in the late 1990s likely influenced Ontario’s allocation of the 2004 federal Health Accord funding to mental health case management and stimulated a renewed and more evidence-informed effort to transition individuals from inpatient settings to community care and living.

In 2000, Paula received a 10-year CIHR/CHSRF Chair in health services research, with a focus on KT. This enabled her to contribute to both scholarship and practice in knowledge translation in the following decade, when she was a champion for and pioneer of methods to involve people with lived experience in mental health services and policy research. Moreover, she sought ways to broaden the creation and sharing of knowledge. EENet, a web-based Ontario Evidence Exchange Network that has grown widely over the last decade, was a vision born during that period.

Paula took great pleasure in mentoring, nurturing and preparing the next generation of health services researchers. She has done a wonderful job; many active in the field today have worked with her or been influenced by her work.

Paula is sorely missed, but her vision lives on in many ways. How fitting that this casebook of notable IKT experiences is dedicated to her. It is a fitting way to acknowledge a pillar of the Canadian and international health services research community who, throughout her exceptional career, touched many hearts and minds.

Foreword

The Integrated Knowledge Translation Research Network (IKTRN) is funded by a Canadian Institutes of Health Research seven-year foundation grant (CIHR FDN# 143237). As our tagline reads, integrated knowledge translation (IKT) is about "doing research with the people who use it." IKT sometimes goes by other names, such as are research co-production, engagement scholarship, participatory action research, Mode 2 knowledge production, and patient engagement. The ultimate purpose of IKT is to increase the relevance and use of research findings in health practice, programs, and policies.

The IKTRN is focused on building the science base and capacity for IKT. Specifically, it aims at understanding how best to support research co-production; uncovering the barriers and drivers of IKT; determining its effectiveness at increasing research use; and identifying the best practices and appropriate conditions for conducting IKT. The network has also prioritized building the capacity of trainees, researchers and knowledge users to study and use IKT approaches. The full seven-year research program is described in the IKTRN's research protocol: https://implementationscience.biomedcentral.com/articles/10.1186/s13012-017-0700-y.

When we launched the IKTRN we wanted to get a sense of how researchers and knowledge users currently work together on research projects. To achieve this, we issued a national call for IKT case examples from the Collaborative Health Care Improvement Partnerships (CHIPS) theme group of Canadian Association for Health Services and Policy Research (CAHSPR). The call invited researchers and/or research teams to describe their experiences using an IKT approach. We asked them to provide background on their project, the evidence that was produced or implemented, who was involved, a description of their IKT activities, and the impact/implications of their project. Our intent was to use the IKT Casebook as an opportunity to document IKT experiences, including the challenges, benefits, and impacts of working collaboratively. We wanted to challenge the theory of how IKT is supposed to work with real-world examples of IKT teams working in different contexts. This casebook represents the results of our initial call.

In this first edition of the IKTRN IKT Casebook, we present 12 cases (7 from CAHSPR members and trainees and 5 from IKTRN members) that describe how researchers partnered with knowledge users, the challenges and benefits of these collaborations, and the perceived impact of working in this way. Many of the cases are co-authored by researchers and knowledge users, while some offer the perspective of the researcher or perspective of the student or trainee using an IKT approach. As we read the cases, several themes caught our attention, as well as some important tensions requiring further thought and investigation.

What first struck us was the diversity of research projects in which IKT approaches were being employed. Many of the projects are situated in clinical settings, ranging from primary to specialist care. The cases span the care continuum, from systems (e.g., patient flow) to broad-based quality improvement or practice guidelines initiatives to individual treatment decisions. Many cases are about experiences with individual time-limited research projects, but one involves interesting observations about the challenges of doing IKT with multiple jurisdictions. Another describes engaging hundreds of knowledge users to prepare a pan-Canadian knowledge synthesis program. There are also cases that describe IKT research with indigenous communities and vulnerable populations such as youth with disabilities, individuals with spinal cord injuries, and seniors. Some cases are about partnerships with policymakers and administrators. These collaborations occurred at the local, regional and national level. The diversity of cases tells us that an IKT approach is applicable and useful for a range of research contexts and knowledge users (including the patients and the public, clinicians, health system managers, policy makers, indigenous communities and others).

The diversity of cases also prompted us wonder whether a one-size-fits-all IKT approach will ever be identified. These cases have led us to ponder the implications of the IKT process and its general role in science. For example, these projects illustrate that the scientist-as-expert model had been disturbed, even abandoned. What does the democratization of the knowledge production process mean for other related systems based on the expert-as-scientist model, such as research funding? The cases presented here demonstrate an impressive level of creativity in terms of outputs and dissemination approaches. How do we measure the impact of knowledge sharing, relationship-building and creativity? What are the implications for the academy if ‘real world’ impact measures are given equal weighting with the more traditional measures of academic success, such as the number of publications, journal impact factors, citations, and research grants.

We asked the authors to describe the challenges they experienced doing IKT. Their accounts prompt several considerations for researchers looking to initiate new IKT projects. Researchers may need to distinguish between knowledge users (those whose problems and issues are being addressed by the research and who are in a position to use the findings to inform their decision making) and stakeholders (those who invest in a project or those who may be interested in the topic but may not be direct users of the knowledge produced). Following this, researchers might consider who needs to be involved at which stage of the research process for effective research uptake. For example, depending on the nature of project, maybe a range of partners (knowledge users and stakeholders) are drawn in at the beginning of the work to identify research questions and again at the end of the work to help with dissemination -- but perhaps only a small core of purposively selected knowledge users are involved in the day-to-day aspects of the research process.

More research is needed on the multiple roles for knowledge users in the research process and the profiles of those who can fill those roles. We also need to learn more about timing. What is the most efficient way to engage knowledge users so that research is a clear benefit to them and not a burden? Another challenge for case authors was keeping partners engaged throughout the life of the research project (e.g., if early grant proposals were unsuccessful or during other times when communication among team members diminishes). A few authors mentioned the considerable time and effort required to establish and maintain research partnerships, while others noted the particular challenge of knowledge-user turnover. It is an interesting question whether researchers should partner with organizations rather than with specific individuals within organizations, who may come ago.

Some authors commented on the need to support knowledge users as many of their jobs do not provide protected time to engage in research or they may not have experience being a co-investigator on a research project. In many cases, this involved providing skills training or role clarification. We were struck by one author's comment that researchers should "encourage partners to be decision-makers *throughout the research process*." The ideal of equally shared decision-making requires not only that researchers devolve power but that knowledge users embrace their roles as co-investigators.

We would like to thank all the case authors for their generosity in sharing their experiences and willingness to describe the positive as well as the challenging aspects of using an IKT approach. We are excited about all the tacit knowledge about IKT that is collected in this first casebook. The IKTRN intends to have regular calls for IKT cases so that we can build on the experiential and empirical knowledge of those doing IKT. We will advertise these calls on the IKTRN website and encourage everyone interested to write up and share their IKT cases with us.

Chris McCutcheon, Anita Kothari and Ian Graham

Pain, Pain, Go Away: Co-creation of a toolbox to standardize pain-assessment

Ashleigh Townley[1], Christine Provvidenza[1], Shauna Kingsnorth[1,2,3]

[1]Teaching and Learning Institute, Holland Bloorview Kids Rehabilitation Hospital; [2]Bloorview Research Institute; [3]Dept. of Occupational Science and Occupational Therapy, Rehabilitation Sciences Institute, University of Toronto

Keywords: pain; children; disability; screening

Background

Cerebral palsy (CP) is the most common childhood physical disability [1]. This complex health condition affects a child's movement and posture, creating many potential sources of pain. One in four children with CP experience moderate to severe persistent pain that prevents them from taking part in everyday activities they want or need to do [2]. This health issue is too often overlooked, as screening for pain in the absence of a direct complaint is not routine.

There is good evidence that screening for pain is an essential first step to managing it; however, the research is fragmented and can be challenging to understand in relation to specialized populations like children with disabilities. Consolidating this information in a multi-resource product, like a Toolbox, could provide an innovative method to move research evidence into clinical practice [3]. The aim of this integrated knowledge translation project was to equip families and health providers with the right tools to "talk about pain".

With increasing recognition of the negative effects of chronic pain for children with CP, we set out to develop the *Chronic Pain-Assessment Toolbox for Children with Disabilities* (the Toolbox). This was comprised of the Registered Nurses' Association of Ontario's (RNAO) best practice guidelines [4], clinical practice points for children with CP, chronic pain-assessment tools [5] and implementation supports for adoption in practice. The aim of the Toolbox was to strengthen chronic pain-assessment practices among clinicians working with children with CP in outpatient clinics. The Holland Bloorview Kids Rehabilitation Hospital Foundation and the Ontario Ministry of Health and Long-Term Care provided funding for this project.

Led by Evidence to Care, EtC: the KT hub at Holland Bloorview Kids Rehabilitation Hospital, the Toolbox took three years to develop and pilot-test, and was co-created by clinicians, patients and families. This is the first Toolbox available to address chronic-painassessment for children with disabilities, using rigorous research methods to develop, implement and evaluate the product and usage in clinic.

Description of IKT Activities

There is a no one-size-fits-all approach to changing knowledge, attitudes and behaviour in health settings, but a co-creation approach can lead to improved uptake and outcomes of innovations [6]. Easy, quick and meaningful participation from diverse audiences is essential to this process.

Multidisciplinary stakeholders were engaged throughout the development and implementation of the Toolbox, including physicians, nurse practitioners, nurses, occupational and physical therapists, medical fellows, management staff, youth and family leaders. These stakeholders were integral to the development of the Toolbox; they provided insight on the pain experience, selected applicable pain-assessment recommendations from the RNAO best practice guideline designed for a general population, created clinical practice points specific to children with CP and informed the selection of clinics and clinical groups to pilot the toolbox.

Initially, three outpatient clinics with high volumes of children with CP piloted the Toolbox for 6 months, giving EtC the opportunity to amend processes before extending their use in the hospital. Out of fifteen tools provided in the Toolbox, clinicians from the pilot clinics selected tools that best fit their clients' needs and could be easily integrated into their busy clinics.

Guided by the KT literature, a tailored, multipronged approach was employed to implement the Toolbox [7-10], using structured frameworks such as the Knowledge-to-Action cycle [11] and the RNAO Implementation Toolkit [12]. Strategies included: champions, tailoring toolbox to the clinical context, education campaign, check-ins, documentation support through a dedicated electronic medical record (EMR) screen, audit and feedback (monthly feedback about pain-assessment and tool use rates given to clinicians) and printed support materials such as scoring cheat sheets.

After the initial pilot process was complete, five additional clinics with moderate volumes of children with CP implemented the Toolbox, using the same tools and strategies chosen by the pilot clinics. Working with our youth and family leaders, additional products were developed to empower and support patients and families to initiate pain conversations.

Impact and Implications

A comprehensive evaluation was conducted by an external evaluator through an audit of the EMR screen, document review, online survey of knowledge, attitudes and behaviour change, interviews with stakeholders and a patient/family survey. The IKT approach was a critical enabler of this work, with the Toolbox fostering change in pain-assessment practices. The greatest uptake occurred in clinics where staff had been involved from inception through selecting pain-assessment recommendations, writing clinical practice points, selecting appropriate tools and engaging with implementation strategies (e.g. education campaign, check-ins).

Between March 2014 and December 2015, 96% of children with pain in this project had a tool and/or strategy recorded in the EMR. Moreover, there was a notable improvement in the documentation of chronic pain in a centralized location. Clinicians were satisfied with the Toolbox, had confidence in it and believed it to be valuable and easy to use; their main concern related to the extra time required to do the assessments during relatively short appointments.

Clinicians felt that the Toolbox led to important changes, such as increases in: Consistency in chronic pain-assessment, use of validated pain-assessment tools, direct language around pain, focus on chronic pain specifically, focus on pain’s interference with and impact on daily activities, documentation leading to better continuity of care and identification of pain previously not managed. Patients/families who used the chronic pain-assessment tools found them valuable, easy to use, appropriate in length and easy to understand.

Broadly speaking, particular areas of strength of the Toolbox included extensive stakeholder engagement, thorough and rigorous processes to ensure use of research evidence, ensuring alignment with organizational priorities and maintenance of a pragmatic focus. Barriers to implementation included staff turnover and engagement, volume of clinical population, implementation of sustainability mechanisms from the start of the project and refinement of implementation strategies based on clinical sub-contexts.

Healthcare is a fast-paced environment and changing practices takes time. Since this was the first project of this scale for EtC, a steep learning curve was experienced. Using deliberate and thorough methods, aligned with known best KT practices, while remaining flexible and pragmatic was key to achieving favourable results. Future similar KT-focused work should consider increasing external stakeholder involvement to enhance credibility and transferability, aligning with broader health system priorities to influence uptake, exploring alternative KT strategies for situations where there is lower engagement and planning for sustainability of the innovation after initial implementation is complete.

Between 2015 and 2016, EtC focused on expanding the reach of the IKT model through facilitating the long-distance adoption of the Toolbox at Gillette Children's Specialty Healthcare in St. Paul, Minnesota. Using a Train-the-Trainer model, the Toolbox was successfully implemented in three clinics while tailoring many of the same implementation strategies to the Gillette context. Early audits revealed that clinicians were motivated and engaged to improve their pain-assessment practice. The Project Lead stated, "*because of our adoption of the Toolbox, our implementing clinicians have assessed chronic pain in over 70% of their pediatric patients who may not have otherwise discussed their chronic pain.*" The relationship between Holland Bloorview and Gillette is ongoing and has been a true example of collaborative KT across borders.

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Development of a collaborative research framework to foster IKT: the example of a study conducted by and with a First Nations, Inuit and Métis community and their academic research partners

Janet Jull[1,2], Audrey Giles[2], Yvonne Boyer[3], Dawn Stacey[1,2], Minwaashin Lodge

[1]Ottawa Hospital Research Institute; [2]University of Ottawa; [3]Brandon University

Keywords: knowledge translation; collaborative; First Nations, Inuit, Métis; decision making

Background

Health inequity is the result of systematic and socially produced differences in health within and between populations; health equity is the attainment of one's health potential, and is only possible when there are equal opportunities to achieve health [1] and no one is deprived from achieving this potential [2]. First Nations, Inuit and Métis populations have the highest rates of health burdens as compared to other general populations living in Canada [3, 4]. Despite the strength and continuity within these societies, they remain among the populations that experience significant health inequity [5].

Mainstream research approaches and practices often fail to engage with all populations; this results in community members being undermined as full and active participants in studies conducted to build research evidence that can be used to address health inequity [6]. In this case, we describe the development of a collaborative framework that was designed to engage with a population, foster a process of integrated knowledge translation (IKT) and be defined as ethical, relevant and useful by community members and their academic research partners.

Description of IKT Activities

This case study example illustrates the collaborative framework that was used by and with a First Nations, Inuit and Métis women's community and their academic research partners in order to culturally adapt a health decision-making strategy. A community-based participatory research approach was used to foster engagement among the community and the academic research participants [7].

United by common concerns and interests, the participants agreed upon and utilized a collaborative framework for a multi-study research project focused on adapting a shared decision-making tool and approach. The conceptual elements of a collaborative framework provided structure for the community-academic collaboration to develop, conduct and disseminate research. Directed by the community-academic research collaboration, the co-created knowledge was used to inform an intervention, in this instance a culturally adapted shared decision-making strategy [8]; that, in turn, fostered a process of IKT.

Limitations included work and time constraints for those in the community-academic research collaboration, as well as reliance upon one facilitator for regular and productive contacts among members. Strengths included contributions to building mutual opportunities for community-academic research capacity, such as meeting requirements for co-authorship in publications. They also included improved research skills and learning about building research-informed knowledge beneficial to society and conducted in ways that are ethical and useful.

The two essential phases for negotiating a collaborative framework for a community-research partnership and the steps in a community-based participatory approach are described as: 1) establish guiding features of a collaborative framework: i) form an advisory group, ii) develop ethical guidance and iii) agree upon underlying theoretical concepts for the research study; and 2) engage in research actions that support co-creation of knowledge throughout study processes. Five steps that detail the process of the research collaboration and foster the process of IKT are listed here: 1) find common ground, 2) form an advisory group, 3) commit to guiding principles, 4) adopt a theoretical approach and 5) conduct research. These steps are further detailed in a peer-reviewed and co-authored publication [8].

Impact and Implications

The case study example used to illustrate the collaborative framework was conducted by and with a First Nations, Inuit and Métis women's community and their research partners. It is an example of IKT used to culturally adapt a health decision-making strategy. A community-based participatory research approach fosters engagement among community and research participants and directs community-research collaboration. The collaborative framework enacted IKT and structured ongoing negotiations within the community-research partnership to ensure that ethical obligations to the research participants and the broader community were met and the goals of the study were achieved. Further work is needed to examine the components of this collaborative framework and the potential application to other forms of community-research collaboration.

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Using an IKT approach in working with university students with and without disabilities to build capacity for supports through engagement and co-creation in disability research

Tram Nguyen[1–3], Julia Hanes[2], Debra Stewart[2,3], Sue Baptiste[2,3], Jan Willem Gorter[1,2,4]

[1]School of Rehabilitation Science, McMaster University;[2]CanChild Centre for Childhood Disability Research, McMaster University;[3]University of Ottawa;[4]Department of Pediatrics, McMaster University

Keywords: integrated knowledge translation; youth with disabilities; knowledge mobilization; engagement

Background

Youth with disabilities (YWD) are defined as individuals 12–25 years of age with developmental, communication, cognitive, or physical disabilities. Recently, they identified a need to enhance access to supports and services due to an existing lack of engagement and awareness.

YWD and parents have voiced the concern "*no research about us without us*" [1], which demonstrates their interest in participating in research and knowledge implementation. YWD, who are often not given enough prominence when they are engaged, have stated "*All the research you are doing is great but it's not what we need to help us."* This case focused on using an IKT [2] approach for working with university students with and without disabilities to build capacity for supports, through engagement and co-creation in disability research. Our primary target audience was McMaster University students with and without disabilities, while secondary target audiences included researchers, faculty and community members.

The project took place at McMaster University, where McMaster University's Forward with Integrity initiative was its primary funder. The Scotiabank Chair in Child Health Research, held by Dr. Jan Willem Gorter, provided 1:1 matched funds. Stakeholders included students, researchers, faculty and community members. There was maximum variation in age, gender, academic background and research experience among students. Many students were representatives or active members within Arts & Science, Life sciences, Health Sciences and Critical Disability Studies.

Description of IKT Activities

The project consisted of one research team that included two students (one having a disability) and three researchers. Researchers on the team worked closely with student members to enable them to take a lead role as this project was created by students for students. Student team members had a crucial role in shaping the research question, developing the research objectives, interpreting the results, as well as disseminating and implementing the outcomes. All team members' input received careful consideration and had equal weight. Disagreements were resolved through team consultations.

One student stated "*As a young adult with a childhood onset disability, there are many projects I have the opportunity to be a part of; however, most are tokenistic in nature, often only wanting my data points. There is a longstanding joke among my disabled friends that we often 'sell our bodies to science'. So, when I was approached by Dr. Nguyen to partner on this integrated knowledge translation project, I was extremely enthusiastic because it was one of the first times I, as a disabled individual, had the opportunity to make change for my own people and not be just another 'data point'."*

We brought students together for an interactive and interdisciplinary knowledge exchange symposium to enhance communication and collaboration with researchers, faculty and community members. Students led the development and execution of the symposium, which included four phases: 1) establishing an inclusive research team, 2) sampling and recruitment, 3) convening the symposium and 4) evaluation and analysis.

An action framework guided the selection of the IKT approach, as the idea for this project came from knowledge users (i.e. students) who sought to impact change working with researchers to voice their needs and concerns. The idea of the interactive symposium emerged in consulting with students, since it was deemed "*more fun to get together and talk to researchers and faculty."* This idea aligns well with available evidence on the effectiveness of a youth-led and interactive approach [3].

Thirteen participants attended the symposium. The diversity within the group allowed for rich discussions. Participants enjoyed the symposium as evident through the results of the pre- and post-symposium surveys. One student stated, *"It was very eye-opening and interesting to listen to the voices of people from different backgrounds with a common interest of disability research.*"

Impact and Implications

Students identified five engagement strategies as: 1) creating a centralized knowledge hub (physical location on campus or online virtual hub) to enhance knowledge exchange, as well as communication and networking among individuals with shared interests in disability research; 2) hosting "speed dating" events between students and researchers/faculty to improve communication and knowledge exchange; 3) hosting monthly lectures/workshops/webinars; 4) capacity building via emailing lists for new opportunities; and 5) peer mentoring to connect stakeholders.

Participation in this project empowered students to advocate for their needs within McMaster University. One student stated: "*As a youth with a disability, it was extremely empowering to be able to take a lead role in a project that would ultimately impact my peers and I. It is a profound feeling to know that I, through my lived experience, have the capacity to partner with researchers and lead to genuine change within my own community… I was able to positively contribute to the project by leveraging my peers, community groups and experience as a participant to improve recruitment and project design. I was also able to ensure that the project was youth-focused throughout."* The project results will be shared with the university to influence future planning for student engagement.

This symposium brought students together across departments within the university and surrounding communities, thus enhancing communication and collaboration that would not have occurred otherwise. A strength of this project was the coming together of researchers to support students in accomplishing a common goal, demonstrating that more can be achieved when researchers work with stakeholders rather than in isolation.

A major strength of IKT is assessing research relevance through input from knowledge users. However, IKT requires extensive time-investment at the outset to build sound relationships with knowledge users for facilitating candid discussions and leveraging expertise. Challenges include maintaining engagement and balancing power differentials to ensure an equalized partnership. In this case, students often stated "*I never saw myself as an expert.*" Strengthening rapport with students, as well as identifying strategies for empowerment would be beneficial for future partnerships.

The findings of this project may be relevant and applicable to other partnerships as the themes have universal resonance. Implications for IKT include: 1) defining tasks, roles and time commitment for members; 2) maintaining an open mind to ideas proposed by knowledge users; and 3) allowing for flexibility and creativity to accommodate the needs of all members.

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Integrating evidence-based methods and knowledge user perspectives into guideline development and implementation

Nadia Y. Bashir[1], Julia E. Moore[1], Marcello Tonelli[2], Rachel Rodin[3], Sharon E. Straus[1,4]

[1]Li Ka Shing Knowledge Institute, St. Michael's Hospital; [2]Department of Medicine, University of Calgary; [3]Global Health and Guidelines Division, Public Health Agency of Canada; [4]Department of Geriatric Medicine, University of Toronto

Keywords: guideline development; primary care; knowledge translation; stakeholder engagement

Background

Evidence-based clinical practice guidelines are readily available in Canada, and evidence from systematic reviews confirms their ability to improve clinical practice and patient outcomes [1, 2]. However, their uptake among clinicians remains low [3-5]. One strategy to tackle this issue is incorporating integrated knowledge translation (IKT) into guideline development; this involves knowledge users (e.g., clinicians and patients) informing the development of guidelines and associated knowledge translation (KT) tools, such as infographics and algorithms, making these materials more relevant and applicable [6].

Developing an evidence-based guideline using high quality studies, however, can seem incompatible with incorporating experiential evidence from knowledge users. Obtaining user perspectives to inform guideline scope or maximize uptake may be appropriate, but the guideline itself must be based on high quality research evidence. Therefore, it is not always clear how researchers or guideline developers can incorporate knowledge users' perspectives. An example is provided below on how the Canadian Task Force on Preventive Health Care's (CTFPHC) guideline development process integrates these two approaches.

Funded since 2010 by the Public Health Agency of Canada (PHAC), the CTFPHC develops and disseminates national, evidence-based preventive healthcare guidelines for use in primary care across Canada [7]. It uses the internationally recognized Grading of Recommendations, Assessment, Development and Evaluation method for evaluating systematic review evidence to develop guidelines [8]. The Knowledge Translation (KT) Program at St. Michael's Hospital [9] leads the CTFPHC’s KT activities targeting primary knowledge users: Canadian primary care practitioners and patients for whom guideline recommendations are intended.

Description of IKT Activities

The CTFPHC’s KT activities include both dissemination (e.g., distributing guidelines and KT tools to knowledge users) and implementation (e.g., using strategies to help practitioners use the guidelines in practice) activities [10]. Informed by the knowledge-to-action process model, activities were selected by identifying barriers to guideline implementation and using behaviour change frameworks (e.g., theoretical domains framework) and theories (e.g., COM-B) to find actions that target these barriers [11-13].

Over the past six years an IKT approach has been embedded in all CTFPHC’s KT activities across the development of 19 guidelines. Initially, knowledge users were involved in usability testing of guideline KT tools. Clinicians and patients reviewed draft KT tools during interviews or focus groups and provided the feedback used to inform the final content, layout and aesthetics of the tools. Over time, however, the CTFPHC recognized the importance of engaging knowledge users as early as possible so its guidelines and tools can be more relevant to them and better reflect their perspectives. Thus, an IKT approach was adopted to engage knowledge users at three points in the guideline development process: (1) when selecting outcomes to include in a guideline’s systematic review protocol, (2) when developing the guideline recommendations and (3) when developing the guideline’s KT tools.

During Stage 1, patients to be affected by a guideline rate the importance of considering various outcomes of a proposed preventive healthcare intervention. This input, collected via surveys and teleconference focus groups with patients and a member of the guideline-working group, informs the outcomes section of the systematic review protocol used for developing the guideline. Stage 2 gathers similar data, after receiving evidence from the systematic review about the relative likelihood of each outcome, and uses it to develop the final guideline recommendations and KT tools, while Stage 3 involves usability testing of the KT tools with primary care practitioners and patients.

To date, the CTFPHC has completed Stage 1 with 85 patients aged 18–78 years across five guidelines, Stage 2 with 62 patients aged 25–78 years across four guidelines and Stage 3 with 89 primary care practitioners and 51 patients aged 18–74 years across 13 guidelines. These knowledge users represented 10 provinces and territories and participated in IKT activities for topics like lung cancer screening, tobacco smoking prevention and treatment in children and bacteriuria screening in pregnancy.

The CTFPHC engages other end users as well, like policy makers, health professional associations and researchers, for 1) prioritizing topic areas for guideline development and 2) reviewing guideline protocols, systematic reviews and recommendations. This supplements the involvement of clinicians and patients, since policy makers and opinion leaders advise on real-world implementation issues and can support dissemination and implementation within their networks.

This IKT approach allows the CTFPHC to capture the perspectives of multiple knowledge users from across Canada, including those from underrepresented groups (e.g., First Nations), and meaningfully engage with them through direct interaction with CTFPHC members and KT Program staff. It is thus aligned with the Strategy for Patient-Oriented Research patient engagement principles of inclusiveness, support, mutual respect, and co-building [14]. Because these activities span the full range of guideline development activities, the KT Program works synergistically with CTFPHC members, CTFPHC's evidence review and synthesis centres and scientific experts from the PHAC in using the IKT approach. The KT Program supports its partnership with these groups by engaging them for developing participant materials, providing regular updates on progress and preparing a final report for each stage of the process.

Annual evaluations of CTFPHC guideline reach and uptake show that the 12 guidelines published between 2010 and 2016 have been circulated online or in print 1,009,214 times. They received 1.2–85.3 million media views each, and 846,218 copies of their accompanying KT tools have been disseminated to stakeholders. In addition, 49–100% of the primary care practitioners sampled reported being aware of guidelines that recommend a substantial change in practice (i.e., breast, cervical, prostate, and lung cancer screening), and 24–63% reported making a practice change based on them.

Impact and Implications

Evidence of CTFPHC guidelines and KT tools informing preventive healthcare at the provider and system levels includes several provincial/territorial healthcare organizations (e.g., Cancer Care Ontario, BC Cancer Agency, and Santé et Services Sociaux Québec) changing their screening recommendations to align more closely with CTFPHC guidelines [15-18]. The efforts of the KT Program, CTFPHC, PHAC and key knowledge users and their representative organizations (e.g., College of Family Physicians of Canada) have facilitated the uptake and impact of CTFPHC guidelines. Although KT Program staff, CTFPHC members and representatives from the PHAC coordinate and conduct key dissemination and implementation activities, the input of knowledge users who participate in IKT activities enhances the implementability of tools and guidelines; and knowledge user organizations disseminate the resources produced to their members.

As its IKT approach evolved, the CTFPHC learned several lessons about engaging knowledge users in guideline development: (1) it is not always easy to explain to peer reviewers why integrating traditional high-quality evidence with knowledge users' experience is valuable; (2) meaningful engagement is often conducted in small groups, limiting the generalizability of user perspectives; and (3) making technical information accessible so that knowledge users can provide meaningful input is challenging, so more research is needed on optimizing knowledge user engagement. Despite these challenges, knowledge users who participated in CTFPHC IKT activities rated their experiences positively and expressed appreciation for the opportunity to contribute to Canadian healthcare.

The CTFPHC incorporated IKT into its guideline development process for a wide range of topics. Therefore, the approach described here may help enhance the relevance and applicability of guideline development in a variety of clinical areas, through knowledge user engagement.

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An INSPIRED Story: How Integrated Knowledge Translation is helping patients with complex chronic needs

Shannon L. Sibbald[1], Jennifer Y. Verma[2], Graeme Rocker[3]

[1]Schulich School of Medicine and Dentistry, Western University; [2] Canadian Foundation for Healthcare Improvement; [3]Division of Respirology, QEII - Halifax Infirmary Site, Dalhousie University

Keywords: scale-up and spread; chronic disease; integrated knowledge translation; quality improvement

Background

Patients diagnosed with chronic obstructive pulmonary disease (COPD) are lost in a healthcare system unsuited to handling the complexities of their care. COPD is complex, affecting the lungs and encompassing both chronic bronchitis and emphysema, making it difficult to breathe and carry out normal activities of daily living.

Over 800,000 Canadians (35years+) live with COPD; they are prone to emergency department (ED) and hospital visits, extended stays and increased likelihood of co-morbidities like depression and anxiety. This group of patients requires a more responsive health system that accommodates the management of their disease through clinical interventions and improved models of care. Among chronic diseases, COPD is the number one reason for ED visits, hospitalizations and increased length of stay across Canada [1].

The INSPIRED COPD Outreach Program**™** was created as a solution to the complex, and growing, needs of patients with COPD. *Implementing a Novel and Supportive Program for Individualized Care for Patients and Families Living with Respiratory Disease* (INSPIRED) was first implemented in 2010 at the Queen Elizabeth II Health Sciences Centre in Halifax, Nova Scotia [2]. The program emphasizes home-based care through self-management, individualized action plans and advance care planning. INSPIRED has successfully improved care throughout the illness trajectory, not only for patients, but for family members and caregivers as well. This program needs to be shared and spread across the country to allow more COPD patients and families to benefit.

Description of IKT Activities

The Canadian Foundation for Healthcare Improvement (CFHI) provided seed funding and support to spread the INSPIRED program across Canada. Teams were given $50,000 in seed funding, as well as tools to adapt the INSPIRED model to local contexts. Arms-length funding and in-kind support from Boehringer Ingelheim Canada Ltd was provided. The collaborative enrolled 19 teams across Canada, including 78 organizations spread across all 10 provinces [3]. CFHI brought together patients, researchers, practitioners, policymakers and industry professionals through a comprehensive integrated knowledge translation (KT) process [4].

Our KT process was driven by a quality improvement lens. Healthcare professionals are turning to quality improvement collaboratives (QICs) as vehicles to improve provider practices and patient outcomes within the field of healthcare [5]. QICs are beginning to demonstrate their effectiveness over the past 20 years; as well as helping to shift the model of care from reactive to proactive within provincial healthcare systems [6, 7]. The pan-Canadian INSPIRED-based quality improvement [8, 9] approach was developed to close COPD care gaps, and also spread and scale evidence-based and patient-centered innovations across provinces within geographical contexts.

A fully integrated and co-created KT approach was used to ensure effective uptake and spread [3]. Researchers and stakeholders were involved in a high-touch facilitator role and interconnected to the entire process. Teams were trained via virtual content webinars, face-to-face workshops and regional roundtable exchanges. Using online learning, peer review and idea exchanges, teams were given the opportunity for cross-team sharing.

Teams were active participants in knowledge sharing, participating in webinars centered on successes, lessons and challenges. Roundtable meetings were designed to allow meaningful interaction and collaboration amongst team leads, researchers, CFHI staff and CFHI faculty, which included interdisciplinary clinicians and QI experts. When complex challenges arose, such as the need for data collection support, CFHI staff, faculty, researchers and team members worked collaboratively to create a solution that would both disentangle the challenge and spread the knowledge across the collaboratives. Patients and caregivers were also involved in the KT process, through their attendance of workshops and webinars, and by informing the curriculum, content delivery and evaluation.

Impact and Implications

The program’s initial success continues to be matched across Canada, showing improvements in both patient care and system outcomes. 18 out of 19 teams adapted INSPIRED successfully to local contexts, acquiring the abilities to assess, design, implement, and evaluate the program. Teams submitted data to CFHI over the course of the collaborative through surveys, progress and final reports and team worksheets. Following the collaborative, key informant interviews and focus groups were conducted. All data provided valuable insight into the KT process, in addition to factors enabling the scale-up, spread and sustainability of these programs.

Teams reported quality of care gains for enrolled patients, as well as greater patient-reported self-confidence in symptom-management and ease with transitions from hospital to home and fewer ED visits and hospitalizations. An initial patient cohort (n=146, where early follow-up data were available) had approximately 80% fewer hospital admissions compared to the period prior to the program, based on 3-months pre-post comparisons. Patients revealed feeling less anxious and more confident in their ability to manage their disease after the program; moreover, hospitalized patients and families reported greater self-confidence in transitioning to a home setting.

Teams, especially senior leaders and decision makers, began to use more evidence-based decision-making. Acquisition of QI skills was reported by 76% of respondents, who went on to implement their skill set in the design of INSPIRED solutions. Context and culture played an important role in program implementation, both as internal factors (i.e. culture of the organization) and external factors (i.e. culture of the sector, community or provincial system). Full-time leadership was recognized as crucial to implementing sustainable programs. Funding and existing collaboration with other community health providers played important roles in the program’s implementation. Notably, teams reported that increasing in-person trouble-shooting / brainstorming and evaluation would be beneficial. Furthermore, though webinars were helpful for bringing the group together regularly and engaging with faculty and CFHI staff, they required more time than was anticipated by the participating teams.

This initiative provided an opportunity to improve the efficiency and focus on effective patient care, and the collaborative demonstrated that spread of innovation is achievable, even with short timeframes. Many organizations that participated in the INSPIRED collaborative plan to build on existing program strategies and interventions to sustain and expand the program to other hospitals or institutions. Little research has been conducted on scaling this initiative up and its impact on sustainability to support the research process. We have begun to explore this process, and we believe the lessons learned through the integrated knowledge translation approach of the INSPIRED COPD program are of value to senior policy and decision-makers where better care, better outcomes and better value are priorities.

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Fostering an Academic-Clinical Partnership to Redesign Care on a Pediatric Inpatient Unit

Christine Cassidy[1,2], Laura Foley[2], Mary-Beth Rowe[2], Shauna Best[2], Janet Curran[1,3]

[1]Dalhousie University, School of Nursing; [2] Medical, Surgical, & Neurosciences Unit, IWK Health Centre; [3]Centre for Research in Family Health, IWK Health Centre

Keywords: pediatric nursing; high dependency care; partnerships; policy design

Background

As a registered nurse and aspiring academic, I often struggle with my professional identity; my clinical and academic colleagues assign vastly different values on research and clinical practice. My two worlds collided in May 2015 when I attended a four-part knowledge translation (KT) workshop series designed to strengthen clinicians' and administrators' research skills for designing a practice/policy change with support from a KT mentor.

Description of the IKT Activities

The Manager of the Medical, Surgical, and Neuroscience Unit (MSNU) at the IWK Health Centre attended the workshop with two MSNU clinical nurse leaders. MSNU cares for approximately 1,950 pediatric patients a year, many of whom are deemed high acuity and require more nursing resources than MSNU is able to provide. The MSNU team enrolled in the KT workshop looking for guidance and support to implement a new model of care, known as high-dependency care (HDC), to improve the quality of care for high acuity patients on their unit.

Thus began a collaborative partnership that has evolved over the past 18 months. Junior and senior KT mentors (CC, JC) worked with the MSNU team using a systematic KT research process to conduct a problem analysis, a scoping review of the literature and a stakeholder assessment of implementation barriers. We used the findings from our exploratory work to design a study aiming to implement and evaluate HDC on MSNU.

Impact and Implications

Our integrated team of clinicians, administrators and researchers brought diverse perspectives to the table. The MSNU clinicians and manager ensured our research questions and methods were relevant to the context and practice culture of the MSNU, while the KT mentors provided an evidence-based approach to address the practice issue.

The integrated partnership faced many challenges and found opportunities for learning over the past 18 months; this provided important insights for future embedded IKT activities. Most notable were the differences in priorities, especially with regards to timelines. We experienced administrative pressures to implement practice changes quickly, but a rigorous KT research process required time to collect and analyze data.

Many benefits, however, stemmed from this partnership. They included the development of relevant practice change questions and research findings for MSNU. Our project has led to an enhanced appreciation of nursing research at the IWK Health Centre, illustrated by my new role as a part-time embedded nurse researcher on MSNU where I will provide sustained KT research support to the team. I've learned that an IKT approach in clinical practice takes time, but its impact is visible almost immediately, as outputs from the collaboration pour directly into the hands of administrators and nurse leaders. Most importantly, I learned that my clinical and academic identities can be used in tandem to ensure that my future research initiatives are relevant and useful for clinicians, administrators and researchers.

If successful in this competition, I plan to use the prize monies to start a pediatric nursing research interest group at the IWK Health Centre. The funds would support a series of events, including brainstorming sessions with MSNU nurses to identify priority research questions for their unit and "Lunch and Learn" sessions to discuss the barriers and enablers to using evidence in nursing practice.

From Coalition to Action Plan: Addressing Malnutrition in Older Adults through IKT

Erin Coates[1,2], Dr. Paul Hasselback[3]

[1]Faculty of Medicine, University of British Columbia; [2]Research and Capacity Building, Vancouver Island Health Authority; [3]Medical Health Office, Vancouver Island Health Authority

Keywords: Integrated Knowledge Translation; Innovative Coalition; Collaboration; Malnutrition

Background

One in two older adults admitted to hospital meets the criteria for malnutrition [1]. Our mothers, grandmothers, fathers, uncles, spouses or even ourselves all can be potentially affected by malnutrition, which is associated with poorer health outcomes [2].

Description of IKT Activities

The authors, Erin Coates and Dr. Paul Hasselback, have taken a lead role in developing and supporting local Integrated Knowledge Translation (IKT) activities to address malnutrition in older adults on Vancouver Island. We have also formed a Malnutrition Coalition, inviting 50 NGOs, clinicians, researchers and decision-makers to come together[a]. Erin organized an initial IKT workshop for the Coalition, where Dr. Hasselback shared national and international best practices, and partners presented local findings, successes, resources and ideas.

The presentation of the initial findings in November 2015 led to the formation of the Coalition and IKT activities in November 2016. These IKT activities included (1) sharing evidence to inform health system and practice; (2) discussing barriers and resources available to support practice change and (3) increased involvement of community, clinicians and decision-makers in research partnerships. Building on the initial workshop, Erin plans to draft an Action Plan that highlights the physical, mental, social and emotional impact of malnutrition and outlines the next

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[a] Partners included professionals from fields of healthcare (Medical Health Officer, Registered Dietitians, Nurses, VIHA employees, Medical Student), academia (Professors of Gerontology, Research Associate and Adjunct Faculty at CCPA and SFU), community (Seniors Organizations, Nutrition-Based Organizations, Canadian Malnutrition Task Force, Nanaimo Aboriginal Center) and government (Nanaimo Municipality Social Planner, Healthy Living & Health Promotion Branch of Population & Public Health B.C. Ministry of Health).

steps to be taken. Dr. Hasselback will follow-up discussions and actions while Erin engages leaders and supports ongoing collaboration[b].

Impact and Implications

The biggest challenge in promoting IKT activities was time, as coalition partners have multiple competing priorities and limited time, preventing further in-depth sharing of ideas. These activities highlight the opportunity for researchers and clinicians to work with community partners to fill resource gaps, as well as the opportunity to engage both practicing physicians and medical students in the IKT process.

Erin learned a lot from this experience, as demonstrated in the following quote: "*Being a part of the organization and facilitation of the IKT workshop was the most empowering experience I have had as a medical student. In my past career as a nurse and in the past year as a medical student, I had never been a part of a workshop that purposefully identified an issue and key stakeholders, facilitated a discussion on the multifaceted nature of addressing that problem and determined tangible steps to solve the problem. This event reaffirmed my belief that the only way to address an issue is through collaboration and discussion. It demonstrated the power of an IKT platform to create changes in healthcare that positively impact the health of our patients. I look forward to participating in more IKT workshops in future and will champion this effective style of collaboration as a physician.*"

We plan on putting $650 of the $1000 award monies from this competition towards registration for the National Health Leadership Conference to deliver an oral presentation on local IKT Coalitions. The remainder of the award will be used for developing and implementing a research project in which Erin is involved, revolving around the impact of care planning on the quality of life of frequent users of Emergency Departments.

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Implementing Shared Decision-Making in Pediatrics: Spotlight on Integrated Knowledge Translation

Laura Boland[1,2], Allyson Shephard[3,4], Margaret Lawson[4,5]

[1]Faculty of Health Sciences, University of Ottawa; [2]Ottawa Hospital Research Institute;[3]Children's Hospital of Eastern Ontario; [4]University of Ottawa; [5]Department of Pediatrics, Children's Hospital of Eastern Ontario

Keywords: pediatrics; shared decision-making; implementation; integrated knowledge translation

Background

Participation in health decisions is the cornerstone to patient and family-centered care; yet, children and their families are inadequately involved in health decisions [1, 2]. Shared decision-making is an evidence-based collaborative approach that promotes patient and family decision-making involvement [3].

High-quality evidence underpins the tools and strategies that promote shared decision-making. For example, patient decision aids translate evidence into lay terms and guide patients and families by making the decision explicit; they provide information about the options, associated risks and benefits, and help them clarify their values and preferences [4]. A Cochrane review showed that patient decision aids improved participation in decision-making, knowledge, accuracy of risk perceptions, decision quality and decisional conflict [5].

Decision coaching occurs when a trained healthcare provider provides non-directive individualized decision support to patients and families. When this is combined with a patient decision aid, adult patients show improved decision-making participation and knowledge [6]. Moreover, a systematic review evaluating shared decision-making interventions targeting parents and/or children suggested similar effects [7]. Although leading pediatric regulatory organizations recommend shared decision-making [8, 9], its implementation in pediatric healthcare is limited [10, 11]. This case study describes the implementation of a shared decision-making program at our pediatric hospital using an integrated knowledge translation approach.

The implementation team consisted of four individuals: (A) Dr. Margaret Lawson, clinician-scientist, knowledge user, pediatric endocrinologist and director of the shared decision-making program; (B) Allyson Shephard, registered nurse, knowledge user and research coordinator for the shared decision-making program; (C) Laura Boland, speech-language pathologist and doctoral candidate; and (D) the former Vice-President of Patient Services at the Children's Hospital of Eastern Ontario (CHEO) who was a knowledge user. Other knowledge users included healthcare providers, parents and children (n=60) who we consulted throughout the implementation process.

The project began in 2009 when Dr. Lawson received a two-year Ontario Ministry of Health Academic Health Sciences Centers Innovation Grant to develop a pediatric shared decision-making program for healthcare providers and families at CHEO, a tertiary pediatric academic hospital that provides inpatient and outpatient health services to approximately 600,000 children and youth [12]. In 2012, Dr. Lawson received a Knowledge to Action Operating Grant from the Canadian Institutes of Health Research (CIHR) (2012-2015) to implement the shared decision-making program in pilot areas at CHEO using integrated knowledge translation (IKT) approaches. Ms. Boland was funded by Queen Elizabeth II Graduate Scholarships in Science and Technology and a CIHR Integrated Knowledge Translation Research Network Doctoral Fellowship.

Description of the IKT Activities

We employed various strategies to foster equal partnership within the shared decision-making implementation team. First, the Vice-President of Patient Services (knowledge user) was a named co-investigator on a CIHR Knowledge to Action Operating Grant. We also presented our program to the knowledge user's management team to ensure her involvement was supported by colleagues. Communication within the implementation team occurred at regular quarterly intervals to keep all members up-to-date about progress and next steps; as all team members were onsite, additional communication occurred via face-to-face meetings, telephone and email.

The team collaborated throughout the implementation process for program design, review of all materials, pilot testing in target clinical areas, outcome evaluation and dissemination. We credit this partnership with significant achievements, including: incorporating shared decision-making into CHEO’s strategic plans, policy and practice; obtaining buy-in from senior administration and healthcare providers; improving shared decision-making knowledge transfer throughout the organization (e.g., media releases, organization-wide promotion); engaging other clinical champions; securing protected time for healthcare providers to attend training and aligning program funding and resources.

To gain a broad knowledge user perspective, we consulted approximately 60 healthcare providers, parents and children. We ensured that knowledge users had the appropriate content knowledge by providing a PowerPoint presentation that described the problem (i.e., insufficient patient/family involvement in decision-making) and proposed solution (i.e., shared decision-making). Furthermore, we asked knowledge users to role play a difficult decision using a patient decision aid, and asked clinical experts to review, provide feedback and approve pediatric condition specific decision aids prior their inclusion in our database (available here: http://www.cheo.on.ca/en/decisionaids).
Using an iterative process, we updated knowledge users about progress and obtained multiple rounds of feedback, which helped shape the program and its tools. For example, they advocated for the presence of a decision coach outside the immediate circle of care, provided suggestions to tailor a generic patient decision aid for families (available here: http://www.cheo.on.ca/uploads/Decision%20Services/OFDG.pdf) and identified clinical and parent champions for the program.

We used the Knowledge-to-Action framework to guide implementation of our shared decision-making program [13]. Implementation strategies were chosen based on research evidence [14]. These included a barrier assessment of key stakeholders (i.e., healthcare providers, parents and children) [15], training healthcare professionals in shared decision-making and decision support strategies [16], improving access to pediatric shared decision-making resources, providing onsite shared decision-making support and involving knowledge users.

Although they are yet to be evaluated, we believe the integrated knowledge translation strategies facilitated shared decision-making uptake, bridging the gap between theoretical and applied knowledge. Our clinician-scientists and knowledge user are respected and trusted leaders at CHEO, so their involvement seems to have given the shared decision-making program credibility among healthcare providers, enhanced buy-in across stakeholders and improved healthcare provider participation in the training sessions. Indictors of success include shared decision-making being incorporated into CHEO's 5-year strategic plan, an award received for advancing patient and family-centered care and the training of over 180 healthcare providers to use shared decision-making. Nonetheless, efforts are still required to sustain and scale up shared decision-making implementation at CHEO. For example, a survey of trained CHEO healthcare professionals revealed that 52% are not using shared decision-making and 32% are only using it occasionally.

Impact and Implications

Data suggested that healthcare providers (n=142) were satisfied with the shared decision-making training, as they rated their self-efficacy significantly higher post-training (pre 3.0±0.8, post 4.1±0.6, $p<0.001$) [17]. Pilot testing of decision coaching via a patient decision aid in the CHEO Diabetes Clinic showed that youth and parents found this intervention feasible and acceptable [18]. As such, the decision aid was incorporated into the clinical pathway and is now offered to all families making decisions about a change in insulin delivery. There have also been unanticipated, yet positive, indicators of impact. After the shared decision-making training, a neonatologist championed the implementation and evaluation of shared decision-making intervention to help parents make difficult decisions about extreme pre-term babies. Field testing showed that the intervention was feasible and reduced parents' decisional conflict [19].

Several factors facilitated the success of our partnerships. Our knowledge user was a senior decision-maker with a complementary portfolio in patient and family centered care and prior shared decision-making expertise, which helped us avoid common obstacles associated with capacity building to achieve full partnership. Additionally, several team members had previous working relationships that facilitated the collaborative process and positive team dynamics. Nonetheless, we did encounter barriers; most notably, the unexpected departure of our knowledge user, CHEO's Vice President of Patient Services, from the hospital. Due to the current environment around hospital financial resources, we have been unable to establish an equally strong partnership with another senior administrator. Consequently, we have perceived less corporate support and investment in our shared decision-making program, with implications on the program's sustainability.

We cannot comment on the extent to which our experience is generalizable to other pediatric contexts or beyond; however, our case highlights several important contributions of an integrated knowledge translation approach for implementation. We found that knowledge users provided invaluable insight that shaped the program, mobilized institutional support, enhanced buy-in from colleagues and improved knowledge uptake within the organization. Our implementation efforts have resulted in the routine use of shared decision-making in pilot clinical areas at CHEO.

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Integrated alliance of knowledge users and researchers to develop a grant proposal

Wasifa Zarin[1], Inthuja Selvaratnam[1], Alison M. Hoens[2,3], Annette McKinnon[3], Linda Wilhelm[4], Cheryl L. Koehn[5], Priscille-Nice Sanon[6], Kim Critchley[7], Sharon E. Straus[1,8], Andrea C. Tricco[1,9]

[1]Li Ka Shing Knowledge Institute of St. Michael’s Hospital; [2]Department of Physical Therapy, University of British Columbia; [3]Arthritis Patient Advisory Board, Arthritis Research Canada; Milan Ilich Arthritis Research Centre; [4]Canadian Arthritis Patient Alliance; [5]Arthritis Consumer Experts; [6]Quebec SPOR-SUPPORT Unit; [7]Government of Prince Edward Island; [8]Department of Geriatric Medicine, Faculty of Medicine, University of Toronto; [9]Epidemiology Division, Dalla Lana School of Public Health, University of Toronto

Keywords: research proposal; stakeholder engagement; grant submission; knowledge translation

Background

In the spring of 2017, Canada's Strategy for Patient-Oriented Research (SPOR) released a funding opportunity, through the Canadian Institutes of Health Research, to support the national coordination and project management of knowledge synthesis and clinical practice guidelines development [1]. The objective of this grant was to foster a concerted and collective approach to evidence-informed healthcare by means of multidisciplinary teams of researchers and knowledge users [1].

The Knowledge Translation (KT) Program at St. Michael’s Hospital seized this opportunity to initiate a Canada-wide collaboration on the grant proposal with policymakers, healthcare managers, healthcare professionals, patient partners and interdisciplinary teams of researchers. The research team, including international collaborators, were studying a range of health conditions and topics, with particular expertise in knowledge synthesis, clinical practice guidelines, knowledge translation and patient-oriented research. Collectively, the vision is to create a rapid learning health system where patients receive the right intervention at the right time by facilitating access to timely high-quality evidence and accelerating its use in decision-making and practice.

Description of IKT Activities

To establish early partnership in the proposed research agenda [2-5], the KT Program engaged patients, healthcare providers, healthcare managers, policy-makers and SPOR-funded entities from the conception of the grant proposal through to its submission. During the lifecycle of the grant application, the KT Program invited over 300 researchers, trainees and knowledge users to collaborate on the grant proposal. The result of this extensive outreach was the successful submission of a grant proposal co-created by a team of 175 policymakers, healthcare managers, healthcare professionals, patient partners and other researchers from across Canada and beyond, using an integrated knowledge translation (IKT) approach [6]. Details of our engagement with knowledge users and other researchers in the grant application are described below.

At inception, the initial engagement with knowledge users and other researchers was made through existing contacts and partnerships of the KT Program. The scope of engagement was expanded through a snowball approach via referrals from existing partners in research. Our intent in establishing these contacts was twofold: 1) to identify knowledge users and researchers available and interested in collaborating on the grant proposal and subsequent governance of the proposed project and 2) to gather a diverse range of opinions on research needs and how best to address the identified gaps in the Canadian research enterprise pertaining to knowledge synthesis, clinical practice guidelines, and knowledge translation.

Initial interest and input on the grant application was solicited through an electronic survey. Moreover, invitees were encouraged to refer additional contacts who might be available and interested in participating in the grant application as either co-applicants (i.e., contribute to proposed activities) or collaborators (i.e. provide specific service related to proposed activities), depending on their interests. Subsequently, two sets of webinars (offered on four different dates) were hosted via WebEx to discuss the preliminary survey results, provide details on the grant opportunity (e.g., proposal requirements, evaluation criteria), and strategize how to operationalize this collaborative grant submission.

Following each webinar, detailed follow-up emails were sent to all attendees to communicate clear expectations, timelines and action items related to the grant proposal. A second electronic survey was sent to participants to identify gaps in the application and gather additional information. Since multiple webinars were held throughout the grant application process, in-depth discussions at different time points allowed for further refinements of the grant proposal.

In addition to the webinar discussions, approximately 50 teleconferences were held throughout the grant application process with smaller groups of individuals, such as patient partners and researchers, to allow more focused discussions about specific components of the application. Moreover, over 50 individuals, including patient partners, policymakers and other researchers, collaborated on the application more closely by either writing or reviewing sections of the grant. Central to this proposed research agenda is the collective conception of an inclusive governance strategy that provides an equal opportunity for all members to be involved in any of the seven committees or subcommittees; representation from all four Canadian regions (central, northern, western, and eastern) was present in both official languages as well as a balance of patient partners and other knowledge users, researchers and research trainees. Furthermore, patient-oriented research being the central premise of the grant, five out of seven committees included chair positions reserved for patient partners.

Impact and Implications

The funding opportunity released by CIHR-SPOR created opportunities for a productive Canada-wide collaboration and engagement with knowledge users and other researchers. Engaging more than 175 researchers and knowledge users on a grant application with a rapid timeline is challenging, but when planned carefully it can be very effective. This engagement helped develop a governance structure that is inclusive of knowledge users and ensured strong IKT across all proposed activities.

Planning ahead ensured that researchers and knowledge users with competing priorities and resource constraints could be engaged fully. At the onset of engagement, we provided a detailed e-mail with clear expectations, description of participant role in the proposal, action items and timelines to allow members of our grant team to prepare for each milestone and engage in informed and efficient discussions during scheduled webinars and teleconferences. We created terms of reference for different types of grant team members (e.g., knowledge users and collaborators) to facilitate role clarity and understanding of expectations. Moreover, our internal KT Program staff offered grant-related administrative assistance to knowledge users and collaborators, such as generating applicant numbers and uploading CVs. Ongoing communication through e-mails and teleconferences to update members on the progress or to follow-up on action items was also maintained. Sending regular reminders helped with survey response rate [7], which was initially low but eventually reached 90%.

Our Canada-wide collaboration brought together policymakers, healthcare managers, healthcare professionals, patient partners and interdisciplinary teams of researchers in various stages of their careers to co-create a grant proposal. The collective goal of this alliance is to establish a pan-Canadian alliance with a governance structure that emphasizes IKT with balanced representation of knowledge users, which include patient partners from each province and territory across Canada across all levels of the governance structure. Moreover, 36 partner organizations provided approximately $11 million of matched funds either as monetary or in-kind contributions in support of our vision to create a responsive and coordinated rapid learning health system facilitated by access to timely high-quality evidence.

In the fall of 2017, our broad collaboration in developing the proposal for this shared vision won the grant competition with an award of $5 million in funding from the CIHR and gave rise to the SPOR Evidence Alliance. The partnership built during the grant application process has fueled interest in continued collaborations through this alliance. For example, a number of knowledge users will be posing queries through our alliance, such as the Nunavut Deputy Minister of Health.

We are now in the process of setting up the query submission process through a centralized website that will be available in the spring of 2018. Regular updates are provided to all members of the Alliance through our monthly newsletter. Since the KT Program engaged with a diverse range of knowledge users, including patients, caregivers, healthcare providers, policy-makers and other researchers in the grant application process, our experiences might be generalizable to other situations.

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Using IKT to Translate the Spinal Cord Injury Physical Activity Guidelines in A Community-Based Organization

Heather L. Gainforth[1], Peter Athanasopoulos[2], Sheila Casemore[2], Amy E. Latimer-Cheung[3], Kathleen A. Martin Ginis[1]

[1]School of Health and Exercise Sciences, UBC Okanagan, Kelowna, British Columbia; [2]SCI Ontario, Toronto, Ontario; [3]School of Kinesiology and Health Studies, Queen's University, Kingston, Ontario

Keywords: knowledge translation; spinal cord injury

Background

The term "spinal cord injury" (SCI) refers to damage to the spinal cord due to trauma or disease. Physical activity offers a wide-range of health and psychosocial benefits to people with SCI [1, 2]; but despite the benefits, the SCI population has been described as one of the most inactive segments of society [2-4]. Health promotion initiatives aiming to promote physical activity in the SCI population are needed but often overlooked [5].

In March 2011, evidence-based physical activity guidelines for adults with SCI were released by SCI Action Canada, a network of researchers and community members that aims to advance physical activity knowledge and participation among Canadians living with SCI [6, 7]. These guidelines were developed using the AGREE II framework, and they outline the amount, intensity and types of activity required to obtain fitness benefits [6].

Guidelines, however, are only as effective as their implementation. SCI Action Canada emerged from a SSHRC Community-University Research Alliance (CURA) grant; its mission was to develop and implement physical activity interventions in the Ontario SCI community [8]. The funding allowed SCI Action Canada to undertake multiple end-of-grant KT initiatives with partners to widely disseminate the physical activity guidelines for adults with SCI. This case outlines how SCI Action Canada used an integrated KT approach to plan and execute end-of-grant KT by partnering with a community-based organization (CBO), SCI Ontario (formerly the Canadian Paraplegic Association Ontario), to disseminate the physical activity guidelines and evidence-based intervention strategies to three target audiences: (1) clients with SCI; (2) people who support someone with a SCI and (3) SCI Ontario staff and volunteers.

Description of IKT Activities

The Partnership

All SCI Action Canada's partnerships are guided by principles of community-based participatory research [9].These include developing strong cross-sector partnerships with stakeholders to co-create and share emerging knowledge, integrating and utilizing all stakeholders' relevant expertise and experience and promoting a sense of ownership and common purpose. SCI Action Canada's partnership with SCI Ontario began when Dr. Martin Ginis (SCI Action Canada Director) was preparing her SSHRC CURA application to develop and implement physical activity interventions in the Ontario SCI community. SCI Ontario was engaged as a formal partner on the CURA grant, which was awarded in July 2007.

While a partnered IKT approach was used throughout the entire research process (e.g. the development *and* implementation of guidelines and interventions), this case study outlines how IKT was used to conduct and evaluate end-of-grant KT activities (i.e. dissemination of the guidelines and interventions). Our group aimed to study and evaluate the implementation of our end-of-grant KT activities, and used an IKT approach to develop research questions, design the studies and analyze and disseminate findings related to the impact of our end-of-grant KT. The research was approved by the Queen's University's General Research Ethics Board.

SCI Ontario and SCI Action Canada signed a memorandum of understanding, and a core research team was developed to disseminate the guidelines within SCI Ontario. SCI Ontario strategically assigned to the project key administrative staff members working in client services, Mr. Peter Athanasopoulos and Ms. Sheila Casemore. Both liaised with researchers and other administrative staff in SCI Ontario; SCI Ontario provided Athanasopoulos and Casemore with time and resources to devote to the project and asked that they not volunteer their time outside of work hours.

SCI Action Canada assigned five researchers to work in partnership with SCI Ontario: Dr. Martin Ginis (PI), Dr. Amy Latimer-Cheung (Co-Investigator), Dr. Kelly Arbour Nicitopoulos

(Co-Investigator), Sonya Corkum (KT expert) and Dr. Heather Gainforth (PhD Student). The researchers followed a hierarchical structure; the PhD student worked with community partners on a regular basis, often speaking with partners multiple times per week and reporting on progress to her supervisor weekly.

IKT Strategies

To foster the IKT partnership, the entire team, including the community partners, met face-to-face bi-monthly. The researchers' expertise ensured that the interventions and evaluations were developed using high quality research. Likewise, the CBO's credibility, expertise and reach within the SCI community ensured that the initiatives and evaluations were adapted appropriately to each context, reached target audiences, and were adopted and implemented. All partners were considered equal, and all informed our end-of-grant KT research questions, methods, analyses and dissemination activities.

Before the research and KT activities began, SCI Ontario outlined their research and organizational priorities, from which the research questions and end-of-grant KT strategies were derived. The partners lead recruitment for and implementation of the KT interventions. The team worked in partnership to develop the evaluation tools; partners outlined key indicators that would be valuable to their organization and the research team provided theoretical knowledge to develop scientifically and locally relevant evaluation tools. Analyses were primarily conducted by the researchers; however, community partners were consulted throughout the analysis process and did inform the findings. Finally, partners worked with the research team to disseminate knowledge of our end-of-grant KT efforts to wider audiences (e.g. newsletters, magazine articles) and were co-authors on all publications.

KT Strategies

Between 2010 and 2013, the team conducted three overarching IKT projects that aimed to disseminate the guidelines and promote physical activity to people with SCI across Ontario. The research questions, methods, analyses and dissemination efforts were all developed in partnership with SCI Ontario.

All projects were informed by theory and frameworks within KT and behavioural science. Frameworks included Diffusion of Innovations Theory, the RE-AIM framework, the

Knowledge-to-Action Framework and the Theory of Planned Behaviour. Project 1 used an event-based Roadshow to reach and persuade people with SCI to consider adopting the guidelines, and also convince support personnel and SCI Ontario staff to promote the guidelines to people with SCI [10, 11]. Project 2 used network analysis to map KT networks within SCI Ontario and examine the role of interpersonal communication channels in the KT process [12, 13]; and Project 3 trained SCI Ontario peer mentors to disseminate the physical activity guidelines to mentees with SCI, using an evidence-based motivational interviewing tool [14, 10].

Impact and Implications

Measures of Impact

In total, five manuscripts, seventeen reports and three magazine articles were published from this work; and the team achieved four of the five RE-AIM factors for health promotion initiatives to have impact [15]: reach, efficacy, adoption and implementation. Across the three projects, the team reached and disseminated guidelines to over 100 people with SCI, 140 support personnel and over 80 SCI Ontario staff and volunteers. At the time of publication, these projects represent the largest reach of any SCI physical activity intervention found in the literature.

Findings regarding behaviour change and adoption of the guidance among key target audiences were promising. Of note, both our pre-post evaluations and the network analysis indicated that interpersonal communication was a facilitator of KT. Likewise, our interventions were adopted by SCI Ontario and implemented as intended. Our evaluation indicates that it was unlikely that this level of impact would have been observed without an IKT approach (i.e. continued co-ownership and partnership through the entire research process; [16]).

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Development of a multi-chronic disease tool (KeepWell) to support the self-management of older adults and the clinical decision-making of providers: an IKT example

Monika Kastner[1,2,3], Leigh Hayden[1], Julie Makarski[1], Yonda Lai[2], Nate Gerber[4], Anu Jhajj[4], Joyce Chan[1], Victoria Treister[2], Sharon Straus[2,5]

[1]North York General Hospital Department of Research & Innovation; [2]Li Ka Shing Knowledge Institute of St. Michael's Hospital; [3]Institute of Health Policy, Management and Evaluation, University of Toronto; [4]QoC Health; [5]Department of Medicine, University of Toronto

Keywords: knowledge translation; self-management; chronic disease management; older adults; multimorbidity; clinical decision support

Background

We aimed to develop an evidence-based, user-informed, multi-chronic disease management tool (KeepWell) that can integrate the care of any combination of the most common high-burden chronic conditions affecting older adults (65+) to meet the needs of an aging and increasingly complex population. To ensure we had the best available evidence on tools that support multimorbidity, we conducted a systematic review to understand which multimorbidity intervention strategies work for older adults and a realist review to determine their underlying mechanisms [1, 2].

To address the lack of comprehensive guidance for rigorously developing KT tools and products, we used our knowledge synthesis findings and consultation with our KT and design experts to create a framework called "Knowledge-activated Tools" (KaT). This framework aims to help a wide range of knowledge users (researchers, providers, policy makers) develop, disseminate, implement, sustain or scale up optimized KT tools and products; it was validated in a Delphi study with 35 KT experts. We applied the KaT framework, in addition to findings from our reviews and input from our IKT team, to create the KeepWell tool.

Description of IKT Activities

In our work, we defined IKT according to Kothari et al.'s description of it as *"the development of a relationship between academic researchers and practitioners and/or policymakers, for the* *purposes of collaboratively engaging in a mutually-beneficial research project or program of research"* [3]. We also used Kitson's co-KT framework [4] to guide the IKT approach of our collective work.

Our IKT team included older adults with multimorbidity (end-users of the KeepWell tool), clinicians (geriatricians and family physicians interested and experienced in optimized multimorbidity management), policy makers (decision makers interested in solutions to address chronic disease management in our rapidly aging population) and researchers with expertise and interest in advancing KT practice and science, health services research, biostatistics, health economic analysis and human factors engineering. A large number of these researchers were involved at every phase of our three-year research project.

An IKT approach was especially appropriate for building our KeepWell tool due to the tool's complexity and the demand for high usability. The KeepWell tool provides customized lifestyle recommendations for any combination of ailments from the top 11 high-burden chronic conditions affecting older adults (e.g., diabetes, heart failure, arthritis, dementia, stroke and depression). To achieve this level of customization for such a large quantity of information, we sought clinical practice guidelines across these conditions and also worked with our clinicians (geriatricians and family physicians) to craft lifestyle recommendations; we focused on tailoring the messaging for the combined diseases, particularly for discordant disease pairs (i.e., those that do not share care processes or risks such as diabetes and COPD). This was necessary because most clinical practice guidelines don't provide recommendations for coexisting chronic conditions.

Our challenge was to create content and logic for different combinations of 11 chronic conditions while keeping the recommendations simple and easy to use and allowing for information to be customizable and able to be generated according to health risks and priorities of tool uses. We expected it would be difficult to balance rigour and comprehensiveness with usability and user satisfaction. In addition, since the area of multimorbidity is nascent, it was crucial to have clinical experts involved, to ensure appropriate interpretation of the disparate evidence.

IKT activities used to support the process included convening the IKT team, identifying expectations about IKT member roles, development of the IKT organizational and governance structure and development of a communication mechanism. We convened an initial IKT team (via email invitations and personal contact with the PI and the core team) comprising ~15 members (researchers, clinicians, policy makers and two patients with chronic conditions). As we advanced through our research projects, we involved other knowledge users such as our patient co-design team of 10 older adults with chronic conditions recruited from the North York General Hospital patient and family advisory group and older adult volunteers from St. Michael's Hospital. Additional members were gained from clinician knowledge users (family physicians, geriatricians) and experts in health services and KT research, human factors engineering, design and e-health technology, biostatistics, and health economics analysis.

IKT member roles were not explicitly defined at the outset, as we anticipated that different knowledge users would be engaged at different milestones of the project where particular expertise would be required. This is in fact what ended up happening. We strategically engaged different types of knowledge users at different stages of the research with specific engagement objectives (i.e. refine scope, review content, assist in implementation), which increased the meaningfulness and efficiency of our knowledge user engagement: 1) researchers and select clinicians provided feedback on all aspects of the research (methods, content, implementation, evaluation); 2) specialized researchers provided specific help with analysis and eHealth technology development; 3) clinicians participated heavily in commenting on content and messaging; 4) older adults helped design the KeepWell tool and provided feedback; and 5) our clinicians will help with the implementation, recruitment and evaluation of our KeepWell tool across their affiliated hospital sites.

We initially convened a core steering group of knowledge users comprised of health services and KT researchers, patients, clinicians and policy makers who were co-applicants in the grant that supported our research project (~15 people). They helped develop the objectives, research questions, study methods, project plan and timelines. It was not possible or practical to engage all IKT members throughout all phases of the project, so we created and published a quarterly electronic newsletter to update our stakeholders on our progress, milestones and achievements. We obtained more regular feedback with key members (co-designers, clinicians) and working groups over email and through small group meetings and held in-person/teleconference meetings with the wider IKT team at key milestone points to discuss progress and next steps.

IKT activities used to support the research included conducting knowledge syntheses, developing the KaT framework, co-designing the KeepWell tool, and monitoring and evaluating our communication strategies. Given our topic was multimorbidity, we had engagement from researchers and clinicians in every aspect of the reviews via meetings and teleconferences. We held meetings and teleconferences to finalize the protocol and search strategy on a monthly basis at first then less regularly; we used email for clarifications about methods, content and analysis.

We engaged our methods and KT researcher experts to ensure that our work was informed by a strong evidentiary base. With each iteration of the framework, we sought feedback from KT experts to clarify the steps, to confirm the logic, and to get a sense of the framework organization and content. The framework was evaluated in a three-round Delphi study by ~35 KT experts, some of whom were part of our IKT team.

Nine focus groups were held with our patient co-design team throughout the tool development, from the exploration stage to the final beta version. Feedback was collected via group discussions, feedback surveys, and observing use of tool prototype versions; these data were used to inform further iterations of the tool. Family physicians, geriatricians and researchers with expertise across different lifestyle domains (i.e., physical activity, diet, caffeine, alcohol, smoking, bladder and weight) reviewed all clinical content.

We monitored the engagement of our stakeholders and administered surveys after each in-person/teleconference meetings to make future communication and engagement more productive and effective. The main decisions from each IKT event were recorded and shared with the members present, as needed.

An unexpected outcome was the emergence of new IKT members with each study that we conducted. This occurred in response to KT activities such as conference presentations, which garnered interest in our work and in becoming active IKT members. We also sought out particular experts to help us with our work, and this naturally progressed to a working relationship and an active IKT membership. However, we also experienced a drop-off of some individuals who ceased active engagement; the most common reason for this was time constraints.

Impact and Implications

Our findings (the KaT framework and KeepWell too) can be used by clinicians to optimize their care for older adults with multimorbidity, and also by our funders, Ontario's Ministry of Health and Long-term Care. The KaT framework has wide applicability because it responds to the challenges to optimized knowledge uptake and decision-making and provides a systematic pathway for a wide range of knowledge users to more rigorously and efficiently create KT tools and products with the best potential for impact.

Our KeepWell tool has great potential to influence chronic disease self-management in Ontario and beyond because 1) it was co-created by older adults; 2) it responds to most identified challenges faced by older adults; 3) its features are innovative; and 4) it has great potential for scale and spread. We anticipate that our integrated and high-level engagement with older adults and clinicians will result in shorter improvement cycles in the usability study and enhanced enrollment in the upcoming evaluation of KeepWell.

Key lessons we took from this experience include: taking the time to build relationships to obtain access to key knowledge user groups, keeping IKT members engaged during long periods of inactivity; planning for and providing adequate time for in-depth feedback from knowledge users; considering different methods to obtain feedback depending on knowledge user preference, and shaping the number, roles and expectations of knowledge users iteratively as the project progresses.

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Scaling Up IKT? Adapting Integrated KT Strategies to a Large Multi-jurisdictional Network

Sara Kreindler[1,2,3]

[1]*The Manitoba Research Council, Health System Innovation;* [2]*The George and Fay Yee Centre for Healthcare Innovation;* [3]*Department of Community Health Sciences, University of Manitoba*

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Background

Patient flow—ensuring that patients receive the care they need, when and where they need it—is a crucial challenge for health systems across Canada. Stagnant flow, while most readily observable as Emergency Department congestion, is widely recognized to be a *system* problem. Yet, in the absence of robust evidence to guide system transformation, decision-makers are rightly cautious about embarking on this difficult and risky enterprise.

This was the context I confronted as an embedded researcher in the Regional Health Authority with the worst Emergency Department congestion in Canada[3]. Our region had recently enshrined patient flow as a top organizational priority; in response, I had conducted a mixed-methods investigation into why a decade of improvement efforts had yielded such meagre returns and found that real improvement would require fundamental system redesign on the basis of certain key principles. Reluctant to plunge into a radical overhaul, leaders called for an examination of flow strategies practiced by similar jurisdictions to confirm whether those principles did indeed underpin their peers' success. Thus began a quest to uncover the sources of inter-regional variation in patient-flow performance.

Description of the IKT Activities

This ambitious venture demanded that I shift from serving as an embedded researcher within a single region to forming research partnerships with every urban health region in Western Canada

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[3] *Note: At around the time we submitted the PHSI application, I transitioned from my position with the Region's embedded research and evaluation unit (in which I had spent eight years) to a university faculty appointment. I continue to work closely with regional management, and increasingly with other groups of decision-makers.*

– a total of ten regions ("zones," in Alberta) spanning four provinces. With each, I undertook a process of securing formal support, gaining access to managers and data and —equally important— enhancing the attractiveness of participation by prioritizing their knowledge needs as highly as our own.

In other words, I endeavoured to scale up IKT. This entailed a two-level IKT strategy of building partnerships with both knowledge-user *organizations* and key senior and middle managers within them. First, I sought to leverage existing infrastructure, including formal multi-regional bodies (specifically the Western Healthcare CEO Forum, its associated Western Patient Flow Collaborative and Accreditation Canada), other regions' internal research capacity and my own well-established relationships with local managers. The CEO of my Region "pitched" the idea to her CEO-Forum colleagues; the locally based co-chair of the Flow Collaborative helped me integrate myself into that group as its first and only researcher-member. From each province I recruited researchers who were embedded or system-engaged (e.g., in hybrid researcher/decision-maker roles).

Scale-up also required tailoring of IKT strategies to build relationships and share control. Supported by a CIHR Planning Grant, I toured the participating regions to meet face-to-face with as many decision-makers as possible, identifying one "point person" per region/zone (usually the middle manager with greatest responsibility for flow), while forming multiple connections as insulation against management turnover.

Synthesizing the comments of over 100 decision-makers, I prepared a discussion document featuring 11 key questions about the planned research, each with a summary of consultation findings ("You said...") followed by implications for action ("Therefore, we will..."); this tool elicited highly positive feedback as well as further input. Having developed a team of 10 researchers and 33 knowledge users, we went on to submit the top-ranked application in CIHR's Partnerships for Health System Improvement (PHSI) competition, securing partnership funds from each provincial agency as well.

While we awaited funding, decision-makers continued to participate in fleshing out the research plan via a combination of e-mail, teleconferences and a face-to-face team meeting (piggybacked on a Western Flow Collaborative event for member convenience and resource sharing). Every aspect of the process—from hospitality to transparent, collaborative decision-making to assiduous care for minimizing participants' administrative burden—was geared towards demonstrating respect and appreciation for our decision-maker partners.

Impact and Implications

We are currently in the data-analysis phase; therefore, some of our most intensive IKT work still lies ahead. Nonetheless, our experience has already yielded some insight regarding the scalability of IKT.

The skills of IKT proved highly scalable. My experience helping decision-makers identify priority questions, communicating effectively with stakeholders and genuinely listening to and incorporating input were readily transferable to a multi-jurisdictional context. Moreover, my familiarity with decision-maker culture and track record of decision-maker driven research bolstered my credibility. The project enjoyed the active participation of diverse decision-makers since its inception.

Much less scalable were the logistics of IKT. Operating within their own organization, embedded researchers—free from any need to "sell" proposals, negotiate access or obtain external resources—can nimbly respond to even the most broad and complex of decision-maker questions. In contrast, the pan-regional scope of this project multiplied its administrative and social complexities. The imperative of winning external funding yoked the research to the hurry-up-and-wait timelines of granting agencies and compelled me to impose the cumbersome requirements of the application process upon decision-makers, while simultaneously striving to relieve them of such burdens as much as possible.

The project's scale also introduced complexities unrelated to IKT; for instance, it took a full year to secure ethics approval from all required bodies. All of this contributed to an unprecedented need for administrative and project-management support, engendering new opportunities for the operation of Murphy's Law. Even worse, pervasive delays, by vitiating the project's ability to generate timely information for decision-makers, threatened to erode the relationships we had worked so hard to build.

What was not scalable at all was the context of IKT. Repeated interaction within a shared environment allows embedded researchers to establish longstanding trusting relationships and also promotes their acquisition of a rich store of knowledge that enhances both relationship-building and research. I had hoped to replicate these conditions by drawing on local research capacity; however, researchers with relevant system-level connections *and* the time or mandate to play more than an advisory role were only present in a few regions. More importantly, embedded researchers can align their research with local decision-makers' specific concerns, a quality that decision-makers from multiple jurisdictions, even when converging on overall priorities, are highly unlikely to share.

Even the most committed researcher cannot turn a disparate, geographically far-flung network of stakeholders into a unitary body of primary intended users; and as the number of knowledge-user organizations (and organizational levels) increases, so does the difficulty of crafting a research plan that pleases everyone, without watering it down to the point of meaninglessness. Indeed, the very concept of *integrating* research into the decision-making process becomes problematic when the parties involved do not share responsibility for the same decision. Facing this conundrum, I entertained the idea of replacing or supplementing the original project with multiple sub-projects focused on local priorities; however, consultation with the stakeholder team revealed this option to be impracticable.

Lest this history seem to be grounds for pessimism, two caveats are in order. First, it should be noted that some of this project's unique features—the vastness and systemic nature of the topic, the shakiness of some of the infrastructure we sought to leverage (e.g., the Western Flow Collaborative has been inactive for the past year) and my own status as a new faculty member with no established lab—no doubt contributed to the magnitude of the challenges encountered. Secondly, it is noteworthy that challenges delayed the project but did not derail it; decision-makers from each region remain engaged, still intend to participate in interpreting the findings and expect to derive valuable insights on an issue of high priority. Nonetheless, our experience illuminates important ways in which IKT and multi-jurisdictional research may resist alignment. Perhaps, when it comes to the co-production of knowledge that can meaningfully inform organizational action, small is beautiful.

IKT
Research Network

The IKTRN is a network of knowledge users and researchers committed to studying, teaching and practicing integrated knowledge translation. The network is supported by the Canadian Institutes of Health Research through a seven-year Foundation Grant (FDN 14237) and is based at the Centre for Practice-Changing Research at The Ottawa Hospital, which is affiliated with the University of Ottawa.

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