

INTEGRATED KNOWLEDGE TRANSLATION CASE NOTES

2021



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FOREWORD

Anita Kothari

I have been living, breathing and *teaching* knowledge translation for my whole career. When the first volume of the Integrated Knowledge Translation Research Network Casebook was published, I immediately started to think about how to *use* these cases. There are now three volumes in the IKT casebook series, representing many scholars' time, energy and research. I didn't want them to be a wasted effort. A number of options ran through my head. Maybe they could be accompanied by boxes that summarize their important contributions in three bullet points. Or maybe we could do a more tailored dissemination effort. Then I wondered if I should broaden my focus. These cases pull back the curtain on how researchers and knowledge users build relationships and plan research projects together. At that point I realized I could try them as a pedagogical tool in my graduate-level knowledge translation class.

Let me describe the IKTRN casebooks before describing how I used them in class. From 2017, the Network has issued annual calls to researchers and trainees for cases about their integrated knowledge translation experiences. The purpose of these cases is to illustrate what is happening on the ground with respect to integrated knowledge translation. The motivation for the casebook series was to: 1) supplement the theoretical literature, 2) capture learnings from those intimately involved with IKT projects (because not everything that happens at the front line gets evaluated or published) and 3) probe deeply into the partnership aspects of IKT. We wanted to know details about the partnership (How was the partnership established? How was it supported?), the perceived link to outcomes and impacts and the lessons learned. Our instructions asked the authors to write a 1500-word, plain language narrative-style account of their IKT approach. We provided constructive criticism to authors to ensure all cases were of a similar quality and provided the same information.

Teaching through the use of cases is an alternative to the traditional lecture-style approach, and it is often used in professional programs such as business or law. A classic case will involve a problem that has multiple possible solutions. Using cases to stimulate class discussions allows the class to share their experience and knowledge about the problem described in the case. Students may need to present sound arguments for the solution they favour, thereby considering different views about the ways to solve the problem.¹ Through this approach, the course material becomes practical and enjoyable.² At Western University, where I teach, the graduate-level, case-based public health program requires students to write a teaching case to demonstrate application of their knowledge from coursework and their practicum experience.^{3,4} Students also learn from previously-written public health cases specific to the Canadian context. A one-page instructor guide/teaching note with keywords, learning objectives and a brief synopsis accompanies each case.

I decided to use the IKTRN cases in a slightly different way. The original authors weren't asked to write their cases for teaching purposes – that is, a problem wasn't highlighted in a way to elicit multiple perspectives through facilitated discussion. I still wanted to use the cases as a way for the students to synthesize their learnings in the knowledge translation class. To do that, the final evaluative component of the class was a written "case note" to accompany one of the cases. Students were free to select any case from volumes 1 or 2, and some selected the same case. I told students that the purpose of the case note was to provide the reader with some background information from journal articles and gray literature with which to understand the case. I provided a template description for them to follow, consisting of:

- a summary of the case;
- identification of two knowledge translation issues raised in the case, plus integrated knowledge translation as the third issue;
- learning goals related to the issues (What will the reader gain from reading the case note?);
- an analysis of each of the three issues for which the student discusses the relevant literature; and
- a conclusion.

I provided some formatting instructions. Early in the semester, I asked the students to present on their case note to the class, summarizing the issues they planned to tackle. The other classmates and I provided oral feedback to each student. I also met with each student to discuss the issues they selected. By doing so I was able to refer them to a particular author who might have written extensively about their issue, or re-frame their issue to focus on an area that I knew had associated literature (sometimes this meant giving them key words to find appropriate literature).

I realized, however, that the students needed some scaffolding to help them successfully write their case note. I incorporated a graded exercise *before* their individual case-note exercise. First, I presented a lecture about case studies and the case-note assignment. Then, students worked in small groups to develop and present a case note to the class. This exercise gave them a chance to do a "dry run" of the assignment they were going to repeat, with a different case, as their final, individual evaluative component. The difference was that they could work through the assignment with peers, and instead of a written case note they prepared a presentation. It also gave me an opportunity to provide feedback about their conceptualization of the assignment.

How did the process turn out? Informal feedback indicated that the students were thankful for the group work that allowed them to understand what the final assignment would look like when they had to do it on their own. Unfortunately, talk about COVID-19 shutdowns coincided with their group presentations, making everyone uneasy. Face-to-face classes were cancelled abruptly soon after. We gathered for online classes to finish off the term, but the combination of everyone's anxiety derailed the planned topics. We were going to discuss integrated knowledge translation for two weeks, but in the end the students had to master the topic on their own using the assigned readings. Instead of the individual presentations, students were asked to record and post their presentation for asynchronous feedback. Despite the last-minute changes, the students did write their case notes. There were no class evaluations on account of the pandemic, so I can't say with certainty that the students preferred this assignment over a traditional final essay. If I were to repeat the assignment I might ask students to hand in an outline instead of the short presentation, allowing me to provide detailed feedback in writing.

The published literature is used in courses like mine to teach about theory, measurement and outcomes related to knowledge translation and integrated knowledge translation. Case studies are another important pedagogical tool that can help learners understand the ins and outs of knowledge translation and integrated knowledge translation in a way that might not yet be captured in the literature. Having students write case notes to accompany the case studies was a successful way for students to demonstrate their ability to synthesize the material and a valuable way to use the casebooks.

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Co-creation of a standardized chronic pain assessment Toolbox for children with cerebral palsy: Let's talk about pain

A case note on:

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SUMMARY OF CASE

Although 25% of children with cerebral palsy (CP) experience persistent pain throughout their lives, ^{1,2} this health issue is often overlooked by health providers. The aim of this integrated knowledge translation (IKT) project was to develop a Toolbox to assess chronic pain in children with CP. This Toolbox incorporates several resources, such as the Registered Nurses' Association of Ontario's (RNAO) best practice guidelines and chronic pain assessment tools. Led by Evidence to Care (EtC), the knowledge translation (KT) hub at Holland Bloorview Kids Rehabilitation Hospital, this IKT project took three years to develop and pilot-test and was co-created by clinicians from a variety of professional backgrounds, patients and families.

The evaluation of the success of this Toolbox was done by an external evaluator, concluding that the greatest uptake took place in clinics where the staff was involved since the initiation of the project. Moreover, after 22 months of the onset, not only had 96% of the children had a tool or strategy recorded in their electronic medical record (EMR), but also the clinicians were satisfied and confident and considered this Toolbox to be beneficial and easy to use. The main barriers to implementation of this Toolbox included, but were not limited to, staff turnover and engagement, utilization of sustainability mechanisms from the inception of the project, and adjustment of implementation strategies based on the contextual demands of each clinic.

KNOWLEDGE TRANSLATION THEMES

Three KT themes are going to be discussed in this case note. The initial focus will be on an implementation strategy that EtC incorporated to facilitate the long-distance adoption of the Toolbox. Aiming to expand the reach of this IKT model, EtC used a **Train-the-Trainer model** and successfully implemented the Toolbox in Gillette Children's Specialty Healthcare in St. Paul, Minnesota.

The second KT theme that I will pursue in this case note is regarding the **sustainability strategies** that such IKT projects can adopt from the beginning of their projects to ensure the continuation of the innovation after the initial implementation phase has been achieved. In this case, the research team identified the lack of sustainability mechanisms as one of the main barriers to successful implementation. Therefore, I will explore the importance of the incorporation of sustainability mechanisms in the early stages of IKT projects.

Lastly, I will elaborate on the **IKT activities** adopted by the developers of the Toolbox. Throughout the development and implementation of the Toolbox, multidisciplinary stakeholders were involved, such as nurse practitioners, physical and occupational therapists, physicians, management staff, family leaders, and youth. These partners collaborated on multiple aspects of the development of the Toolbox, which I will further discuss in the analysis section.

LEARNING GOALS

This case note encompasses three learning goals, which follow the KT issues raised in the previous section. These learning goals are as follow:

- 1. Understand the Train-the-Trainer model in healthcare
- 2. Understand the importance of sustainability mechanisms for KT interventions
- 3. Understand IKT and its importance in the success of KT interventions

ANALYSIS

In this section, I have reviewed the literature and elaborated on each KT theme, hoping that the reader would achieve the learning goals mentioned above by reading this analysis. The analysis is broken down into three sub-sections for ease of understandability.

Understanding the Train-the-Trainer model in healthcare

Train-the-Trainer models are programs where the basic idea is the initiation of a training cascade through teaching skills and knowledge to a small group of trainees.³ These trainees receive instructions on how to train, monitor, and supervise other trainees, and consequently, become the trainers themselves.³ According to a systematic review of 18 studies that administered a Train-the-Trainer model for health and social care professionals, this model had favorable effects on the knowledge of the participants, improved the clinical behavior, and yielded better patient outcomes.⁴ This pyramidical structured teaching method leads to a drastic reduction of resources, staff, and the time necessary to train the therapists effectively.⁵

With the incorporation of the Train-the-Trainer model in the current IKT project, the EtC was able to successfully implement and tailor the Toolbox for the screening of the chronic pain in children with CP in different clinical contexts. These promising findings are reflected by the early audits, revealing that the involved clinicians were more motivated about the improvement of their pain assessment skills through the use of the Train-the-Trainer model.

The Train-the-Trainer model has been adopted by a vast number of studies, with different terminologies, for instance, "training of trainers," "cascade training," and "training the trainer." Examples of such studies are as follows:

- Programs for youth cognitive behavior therapy,⁵
- Educating community program clinicians to do motivational interviewing as an evidence-based treatment for addiction,⁶
- Educating program directors and health educators on how to train HIV-positive peers regarding HIV care and treatment, called "building blocks for peer success" program,⁷ and
- The "HealthMatters" program to improve health among adults with intellectual disabilities.⁸

Despite the popularity of the Train-the-Trainer model in multiple disciplines, this model comes with a few shortcomings. There is a lack of empirical evidence on the long-term sustainability of this model.³ Over time, this training cascade is impeded by several factors, such as the attrition among the new trainers or the scarcity of resources to assess the fidelity of the training.³ To tackle this setback, Mormina and Pinder have developed a conceptual framework that accounts for the sustainability issues associated with the Train-the-Trainer model, recommending that multiple factors are affecting the sustainability of this model.³ The TRAIN framework outlines five constitutive elements of Train-the-Trainer model, which are Talent, Resources, Alignment, Implementation, and Nurture.³ This framework is assumed to have three levels of impact, which are individual, organizational, and supra-organizational (i.e., national and international).³ Although there is still a lack of empirical evidence on the TRAIN framework, incorporating this framework enables researchers to have a better understanding of the implementation of IKT projects using the Train-the-Trainer model.

In recent years, there has been growing interest in e-learning supported Train-the-Trainer programs. The results of a recent study suggest that the Train-the-Trainer program in an e-learning format may be as efficient as the face-to-face-training, resulting in improved guideline adherence, self-perceived knowledge, and confidence of healthcare professionals. I believe that incorporating an online Train-the-Trainer in future IKT projects would increase the sustainability of such projects. I will discuss the sustainability mechanisms for KT projects in the next KT theme as follows.

Understanding the importance of sustainability mechanisms for KT interventions

Sustainability of KT interventions is one of the critical components of the action cycle of the knowledge-to-action framework, intending to ensure the continuation of the program, integration into an existing system, fidelity, and expansion. Also referred to as 'long term,' 'maintain,' 'sustainment,' and 'adhere,' several controversial definitions of sustainability exist in the literature. Buchanan et al., sustainability is "the process through which new working methods, performance enhancements, and continuous improvements are maintained for a period appropriate to a given context, the whereas, according to more recent publications, sustainability can be defined as "the extent to which a KT intervention continues after the adoption has been secured."

It is of paramount importance to plan sustainability strategies for KT projects in the early phases of their development, to assure the long-term quality of care for patients. ¹³ It is even more critical to plan the sustainability of the KT projects targeting people with chronic conditions, as the course of such conditions lasts throughout the life span of the involved people. Nevertheless, this need is often overlooked by the researchers. The results of a scoping review of 103 publications on KT interventions for chronic disease

management revealed that only a few studies made arrangements for long-term sustainability of the innovation after the achievement of the initial implementation.¹³

Although the target population of the Toolbox developed in the current IKT project was children with CP with chronic pain, of whom 25% will continue to experience pain throughout their lives,² the EtC did not plan for the appropriate sustainability mechanisms. Nevertheless, the EtC did identify the lack of sustainability mechanisms as one of the limitations of this IKT project, prompting future research to implement sustainability in the early phases of their projects.

Several frameworks have been proposed for implementing and measuring sustainability interventions. ^{14,16} Fleiszer and colleagues did a concept analysis for the sustainability of healthcare innovations, proposing a broad conceptualization for sustainability, which consisted of 'benefits,' 'routinization or institutionalization,' and 'development.' ¹⁶ They also suggested that a variety of preconditions or factors influence sustainability, which are "innovation-, context-, leadership- and process-related." ¹⁶ Fox and colleagues developed "a theoretical framework to support the research of health service innovations." ¹⁴ This framework reflected the dynamic nature of sustainability and identified five key interacting factors that influence sustainability of health service innovations, which were political, organizational, financial, workforce and innovation-specific factors. ¹⁴ These theoretical frameworks lack empirical testing to date, are still evolving, and need further refinement; however, they are probably useful to develop and implement IKT interventions.

I believe that a possible sustainability strategy that EtC could have explored was integrating this IKT project into the school programs of children with CP. Schools are often acknowledged as being optimal sites for administering large scale programs across several years. Therefore, I would like to make an example of a qualitative study, measuring opportunities and challenges for sustainability of an "evidence-based mental health promotion program in Canadian elementary schools." The WITS program, standing for "Walk away, Ignore, Talk it out and Seek help," was developed to reduce peer victimization and bullying in elementary schools. This program started in 1998 and is now implemented in over 1,300 elementary schools in Canada (www.witsprograms.ca). According to the results of this qualitative study, sustainability of a program at the schools requires commitments of multiple stakeholders, such as community leaders, teachers, and administrators, as well as children and their parents. Several factors seem to be affecting this commitment, with 'supporting the school leaders and program champions' being the most important one. Several factors are program to the parents of the parents.

Understanding IKT and its importance in the success of KT interventions

IKT is a research model, where researchers work collaboratively with knowledge users, aiming to integrate knowledge users throughout the research process. ¹⁹ In the recent years, a matter of growing concern has been the issue of research under-utilization, and that the produced knowledge does not reflect the needs of the healthcare system or takes too long to be absorbed in practical settings. ²⁰ IKT endeavors to tackle the problem of research under-utilization, hence filling in the know-do gap by producing research that is relevant to the knowledge user problems. ²¹ On one side, knowledge users, who know the context, identify a problem and determine if there is a potential for implementation of that research. ²² On

the other side, researchers possess methodological and content expertise.²² Also known as knowledge coproduction, this model emphasizes sharing of power between the knowledge users and the researchers.

The current IKT project engaged multiple stakeholders, including physicians, nurse practitioners, nurses, physical and occupational therapists, medical fellows, management staff, youth, and family leaders. These stakeholders were involved in multiple stages of development, implementation, and dissemination of the Toolbox, each contributing to different pieces throughout the process, which were as follows. The involved healthcare providers and EtC were mostly involved in selecting the most appropriate pain assessment recommendations from the RNAO best practice guidelines and informing the selection of clinics to pilot test the Toolbox. At the same time, the youth and family leaders provided insight on the pain experience. This IKT project was successful in developing and implementing the Toolbox for the assessment of chronic pain for children with CP, owing hugely to the partnership with multiple stakeholders. An external evaluator measured the success of this IKT project through document review, an audit of the EMR screening, an online survey of knowledge, interviews with stakeholders, attitudes and behavior change, and a patient/family survey.

Several IKT tools have been proposed to increase the engagement of knowledge users in IKT projects, as described by Kothari and Wathen. Examples of such tools are the technique of concept mapping, social network analysis (SNA), and narrative formats. He concept mapping technique promotes the engagement of knowledge users through a systematic conceptualization of actionable knowledge by adding data based on their expertise into software. By doing SNA, findings can be converted into sociograms, easily understandable illustrations of the analyses, to better convey the research findings to the knowledge users. Lastly, the narrative formats facilitate the common understanding of local contextual knowledge and unfold the blending of facts as a holistic story. There was no clear description in the current IKT case on whether or not they used any of the aforementioned IKT tools (or any other methods) to increase the involvement of the knowledge users in the research process; however, they mentioned that future IKT projects should focus on enhancing the engagement of the knowledge users.

Despite the promising results associated with IKT, researchers must be aware of some considerations and risks when incorporating this model of research. The facilitators and the barriers of IKT are currently understudied. As suggested by Kothari and Wathen, future research should focus on developing concise determinants of IKT outcomes and impacts. ¹⁹ Moreover, one ethical issue that the researchers should bear in mind when working collaboratively with knowledge users is that the lack of immediate positive results might appear disappointing to the knowledge users. This, in turn, might affect the IKT relationships, and even lead to the discontinuation of the collaboration. ¹⁹ Another risk associated with IKT is that since the knowledge users are often in charge of bringing the pre-identified problems to the table, there would be no room for the researchers to come up with innovative ideas. ¹⁹

CONCLUSION

The conclusion of this case note is three-fold, each associating with one of the discussed KT themes. Regarding the Train-the-Trainer model, although the EtC did not provide a detailed description of the administration, they successfully tailored and implemented the Toolbox in the Gillette Children's Specialty Healthcare in the USA. This is an outstanding example of IKT collaborations across borders,

which adds to the wealth of knowledge on the already established favorable outcomes of the Train-the-Trainer model in the healthcare field. Sustainability mechanisms for the Toolbox were not established by the EtC. Not planning for sustainability after the achievement of the initial implementation is common in the healthcare field, as the concept of sustainability is new, and there is a dearth of empirical evidence on the appropriate strategies. Nevertheless, it is crucial for IKT projects involving people with chronic conditions, such as the Toolbox, to plan for the sustainability of their innovations in the early stages of the development. Finally, regarding the IKT theme, this IKT project was successful in establishing ongoing collaborations with multiple stakeholders, which led to the co-creation of the Toolbox.

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Coexisting systems of knowledge: Using an integrated knowledge translation approach in historically marginalized communities

A case note on:

Jull J, Giles A, Boyer Y, Stacey D, Minwaashin Lodge. 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. In: McCutcheon C, Kothari A, Graham ID, editors. *How We Work Together: The Integrated Knowledge Translation Casebook. Volume 1.* Ottawa, ON: Integrated Knowledge Translation Research Network. 2019; p. 12-14. <u>Available here</u>.

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SUMMARY OF CASE

Health inequity can be understood as the avoidable and unjust differences in the health and wellbeing of certain individuals within a given population, as a result of being denied equal access to the services and resources that are crucial in the maintenance and improvement of their physical health and overall wellbeing.^{1,2} In Canada, one of the most prominent examples of health inequity can be observed within First Nations, Inuit, and Métis (FNIM) socio-cultural communities, where historical, legal, and economic circumstances have resulted in significant health disparities when compared to non-Indigenous Canadians. In a 2018 study, researchers Jull, Giles, Boyer, and Stacey sought to examine the reasons why health research and healthcare policy continue to bring about improvements in the health and wellbeing of the broader Canadian public, but have been unsuccessful in instigating real and lasting change in the health and wellbeing of Indigenous Canadians.^{1,2} The authors of the case study to follow attributed these shortcomings of Western-informed research to the fact that, typically, mainstream research fails to meaningfully engage with the populations and communities of interest. This results in a prioritization of Westernized beliefs and values at the expense of the needs and values of the community itself. This imbalance will not be corrected simply by involving Indigenous community members in the standard research process because the Western-informed practices are themselves a product of a long history of colonial oppression.^{1,2} In recognition of this deeply rooted obstacle, Jull et al. have argued for the need to develop a new collaborative framework that is designed through an equal partnership with the Indigenous communities themselves. Through a collaborative partnership with an Indigenous community-based organization, the Minwaashin Lodge, Jull et al. have constructed a collaborative framework that is designed to foster a process of integrated knowledge translation and is determined to be relevant and ethical according to the Indigenous community's values and needs.¹

KNOWLEDGE TRANSLATION THEMES

In this study, the authors primary intention was to facilitate an equal collaborative partnership with Indigenous community members in the co-creation of a framework that could be used to guide academic research while promoting ethical, relevant, and effective outcomes in vulnerable populations. In order to achieve this goal, the collaborating partners employed numerous principles associated with integrated knowledge translation (IKT), or the co-production of research.^{1,2} The two IKT principles that appear to have played particularly significant roles in the development and mobilization of this study are identified as the early and ongoing engagement with the knowledge users,^{1,2} and the importance of shared decision-making.^{1,2} Each of these concepts will be elaborated upon further in the following sections, but first it may be beneficial to explain the assumed distinction between IKT and traditional knowledge translation (KT) as it pertains to the case in question.

IKT vs. KT

In the traditional sense, knowledge translation can be understood as the processes involved in bridging the gap between knowledge derived from research and theory, and the practical application and use of knowledge in practice.³ In the context of health research, this would describe the process of using research evidence to inform and improve health systems practice. However, as mentioned in the introduction to this case analysis, Jull et al. have argued that the traditional KT practices used in contemporary research are products of the Western-informed academic environment.³ Therefore, whether it be deliberate or inadvertent, these practices will inherently serve to reinforce the colonial oppression of marginalized populations, such as the vulnerable Indigenous Canadians.³ On the other hand, integrated knowledge translation is an approach to research that requires researchers to work as equal partners with the people and community for whom the research is meant to be of use.³ In this case study, Jull et al. construct the project around the principles of IKT in their collaborative partnership with the Minwaashin Lodge so that the needs, goals, and outcomes are all directly determined by the community itself and not by the Western-informed notions of success.^{1,2,3} The IKT approach also plays a role in informing the two principle knowledge translation concepts of knowledge user engagement and shared decision-making.^{2,3}

Knowledge user engagement

The concept of knowledge user engagement is frequently alluded to throughout the stages of this study, and is a fundamental principle of IKT approaches to research. The knowledge user refers to the individuals and communities that are the focus of and affected by the research taking place.³ In this case study, the knowledge users are the Indigenous community members who face the challenges of health inequity, and they are represented by the Minwaashin Lodge community leaders.^{1,2} The early and ongoing engagement with knowledge users is essential in every stage of the research process, starting from the initial identification of the community needs, through the development of the research questions, methods of data collection and analysis, deciding how to mobilize the findings, and determining what metric will be used to assess the success or failure of the outcomes.²

Shared decision-making

The second IKT theme that had a significant influence over the various stages of this case study is the emphasis on involving the community partners in the process of shared decision-making.^{1,2} Effective IKT and user engagement cannot be appropriately practiced without ensuring that the community partners are

involved in the shared making of decisions. This does not simply mean that the researchers asked the community members for their input on the study, but rather all decisions were collaboratively agreed upon without a prioritization of the opinions of one side over the other. The underlying principle here is that the knowledge systems of the research professionals regarding concepts of ethical obligations, methods of inquiry, and research practices were open to modification or even substitution in favor of practices and beliefs that were more relevant to the Indigenous community. Some examples that will be discussed in detail in the following sections include the use of a medicine wheel and OCAP ethical principles, which were determined to be more applicable to the beliefs and values of the Indigenous communities than the Tri-Council Policy Statement that is commonly used in Canadian research.

LEARNING GOALS

In this case study, Jull et al. have sought to employ a collaborative research approach informed by the principles of integrated knowledge translation with a particular emphasis on the early and ongoing engagement of knowledge users (the Indigenous community members) and the use of shared decision-making strategies in order to develop a collaborative framework that would be defined by Indigenous community members as ethical, useful, and relevant.^{1,2} In the following case note analysis, each of these core concepts will be elaborated upon first by examining the concepts themselves as they are discussed in the existing academic literature, and then by exploring how each concept has been applied to the case in question.

As such, the following sections are intended to provide potential audiences with a deeper understanding of three fundamental concepts:

- 1. The importance of implementing early and ongoing knowledge user engagement strategies, particularly in situations involving vulnerable and historically marginalized socio-cultural communities;
- 2. How and why interventions that incorporate shared decision-making techniques result in significantly improved outcomes for communities faced with socio-cultural inequities; and
- 3. How integrated knowledge translation as a collaborative practice can facilitate an environment where multiple systems of knowledge can coexist.

ANALYSIS

Knowledge user engagement

Within the scope of contemporary academic research there has been a growing discussion concerning the appropriate level of involvement that participants should have in the development and conduct of studies.⁴ This conversation has taken a particularly prominent role in the healthcare field, with a growing support for transitioning patients from passive recipients of care, into active participants in the maintenance of their health and wellbeing.^{3,4} In the applied healthcare arena, the proposed benefits of increasing patient involvement range from a greater ability to address the real-world needs of individuals, to an increase in the healthcare system efficiency by doing away with time consuming and costly redundancies.⁴ The roles in this case are modified by bringing the patient closer to the healthcare professional, but they are not completely blurred as the provider remains the expert and the patient remains the recipient. In the field of health research, however, the distinction between professionals who conduct the research and the participants who are the subject of inquiry is propped up by decades of institutional reinforcements, the

very purpose of which has been to solidify the permeance of these roles.⁴ This systemic prioritization of the knowledge systems linked to Western-informed academic inquiry is the precise feature of health research that Jull et al.^{2,3,4} have sought to overcome through the use of the principles of integrated knowledge translation in their collaborative case study. Within the context of IKT approaches to research, the involvement of individuals outside of the mainstream academic research team is typically referred to as the engagement of knowledge users.^{3,4} The phrase "knowledge user" can broadly be understood as referring to those whom would be most affected by the results of a given study. 4 This can include the would be research participants, individuals who are part of a larger community, those with professions that might be influenced by the results of research, or even the policy makers who will base their decisions on certain findings.⁴ Whomever the knowledge user is, the main point to understand is that in integrated knowledge translation, the knowledge users should be "the key partners and contributors of expertise in the co-production of research evidence." If this concept is applied in academic research, then the exclusivity of the research professional's role will no longer take the priority over the knowledge systems, values, and needs of others. Furthermore, by expanding the role of the knowledge user researchers open themselves up to a diverse array of perspectives that can be used in the development of more culturally relevant, ethical, and effective research practices. ^{2,3,4}

With a general understanding of what knowledge user engagement is, it is now possible to explore why this concept is so crucial in studies concerned with vulnerable and historically marginalized communities. The first and perhaps most apparent justification has to do with the fact that knowledge user engagement exists in direct opposition to the idea that the perspectives of academic research professionals are superior. and thus should be held in higher regard than those found amongst the general public.^{3,4} When this hierarchy of expertise is removed from the equation, a space for negotiation and relationship building takes its place, and it is in this space where the research venture can truly begin to take shape.² This understanding sets the stage for the early phases of a study involving vulnerable populations; however, it is not sufficient for the research team to acknowledge the importance of engaging knowledge users by attempting to reduce the distance between "us and them." Leeuw et al.⁵ argue that even with the best of intentions, if vulnerable and historically oppressed populations are absorbed into a research process that is itself a product of colonial dominance, then we are essentially only bringing the problems to the doorsteps of those marginalized communities.⁵ While this deeply rooted barrier may never be truly overcome by an adherence to a particular framework or theoretical approach, one way that research can be conducted in acknowledgment of this issue is to establish early friendships and relationships with members of the community that are situated outside of the research agenda.^{3,5} This early engagement with the knowledge users lays the foundation for the collaboration which will follow, but does so on mutually negotiated terms.² From here, the needs and potential for research can be explored without the influence of prior assumption. Here, one might find themselves questioning the coherence of the case study of interest due to the fact that Jull et al. and their community partners were attempting to develop a framework, which is itself a concept that primarily applies only to Western-informed research practices. 1,2 The truth is that many community-based partnerships with vulnerable populations do claim to engage knowledge users as full members of the research team while at the same time attempting to advance Western-informed professional agendas.⁵ This occurrence might be described as engaging in "tokenism" or the attempt to be inclusive to certain members of socio-cultural communities in order to add a perception of authenticity to the research.³ This does not appear to be the case in the study in question as the research team has devoted

themselves to remain engaged with the community members throughout the project development and beyond the dissemination of the projects results, but it is worth acknowledging as a real and damaging practice.⁵

Shared decision-making

Once the knowledge users and the researchers have developed a trusting relationship and the principles of user engagement have set the stage for the research partnership to begin, the next key concept involved in IKT-informed research concerns the use of shared decision-making (SDM).^{2,3} In broad terms, shared decision-making is defined as a process by which the knowledge users and the research team collaboratively negotiate the parameters of the study, the needs to be addressed, the ethical principles to be followed, how data will be collected and assessed, how the findings will be mobilized, and what metrics will be used to determine the success or failure of the study's overarching goals.² In other words, IKT research approaches require exhaustive collaboration at every stage where a decision is made and a plan is constructed. In applied medical environments, research has shown that engaging patients in the shared making of treatment decisions can lead to increased compliance and overall improvements to patient satisfaction. With regard to medical treatment, these decisions are often supplemented by the use of patient decision aids, which help to clarify the options and outcomes while also providing an opportunity for patients to make choices based on their personal values and priorities. In health research, however, the use of SDM strategies is complicated by the fact that decisions typically require a level of methodological familiarity, health literacy, and an understanding of the academic research process. This situation is further complicated when collaborative research efforts are situated in disadvantaged and marginalized communities which, as a result of their social-marginalization, have not had access to the educational and economic privileges that form the basis of academic institutional knowledge systems.⁶

How then, can SDM be used to improve the outcomes for communities faced with socio-cultural health inequities? In order to answer this question, it is helpful to turn our attention back toward the case study that is the focus of the assessment¹ before exploring what has been discussed in the existing literature. By examining the processes employed throughout Jull et al. and their collaborative partnership with the Minwaashin Lodge² we can see that the research team did not simply ask the community members what they thought the project should look like. They did not restrict their involvement to that of facilitation and resource backing. Rather, what Jull et al. did was commit to a partnership that was not governed by deadlines, progress reports, or the completion of tasks. This partnership was based on the necessary and mutual agreement that traditional research agendas have, up to this point, been unsuccessful in bringing about positive improvement. Therefore, this collaboration would be based on the holistic and sincere desire to identify the real problems, to attempt to find solutions, to mobilize those solutions, and to assess the outcomes. As was the case with knowledge user engagement in vulnerable communities, in order to utilize SDM strategies the researchers had to actively immerse themselves within the community and place a priority on building respectful relationships as individuals as opposed to building partnerships between researchers and participants. When this authentic partnership began to take form, the unique and valuable knowledge systems and areas of expertise from all those involved could begin to be shared, unified, and celebrated without the need to worry that one field of knowledge was overtaking the other. There are several examples of how this SDM evolved and influenced the research partnership, such as the commitment to an ethical guidance that was informed by both the standard Tri-Council Policy Statement,

and the Indigenous-created principles of Ownership, Control, Access, and Possession (OCAP).² The academic literature that touches on the use of SDM in marginalized communities is limited, but from what can be found it is clear that the strategies employed by Jull et al. are appropriate in their prioritization of building real relationships, the cohabitation of knowledge systems, and the unique value of differing areas of individual expertise.^{2,5}

Integrated knowledge translation

Up to this point, the intention has been to explore the academic literature in order to provide a deeper understanding into the reasons why knowledge user engagement and shared decision-making can enable researchers to elicit observable and lasting improvements to the health and wellbeing of vulnerable and historically marginalized communities. These two concepts can be understood as occupying distinctly important but coexisting and intimately related sides of the same coin. Effective knowledge user engagement fosters the opportunity to practice SDM, and the concept of SDM is the underlying principle behind knowledge user engagement. The fundamental purpose behind each of these principles might be described as the promotion of a mutual and inclusive coexistence of different knowledge systems coming together to share in the collaboration of unique perspectives and fields of expertise. This is primary goal for integrated knowledge translation approaches to research, which seek to provide a space for multiple systems of knowledge to coexist without the prioritization of certain values, beliefs, and world views over others.³ There are multiple examples within the academic literature that draw a direct link between the health inequities facing Indigenous Canadian communities and the ineffectiveness of public health programs that fail to acknowledge and account for the existence of non-westernized notions of health and wellness. ^{2,3,4,5,7,8} IKT has been proposed as having the potential to overcome this narrowly conceived understanding of knowledge systems, as it enables researchers and knowledge users alike to identify and develop knowledge that is useful, relevant, and applicable to a diverse array of contextual circumstances.³ In the context of the case study under assessment, the IKT approach to research has been employed in order to create a space where both Indigenous and Western-informed systems of knowledge do not simply coexist, but collaborate and evolve using the unique expertise from each in the development of a holistic and versatile set of principles that can address the community needs while being relevant and ethically sound.

CONCLUSION

In Canadian Indigenous communities there can be observed a historically based and persistent inequity in the level of health and wellbeing of community members that is drastically lower than non-Indigenous Canadians. ^{1,2,3,5} Traditional Western-informed research endeavours have been relatively successful in bringing about improved health standards for the majority of Canadians, but have repeatedly failed in bridging the health inequity gap amongst the most vulnerable and marginalized Canadian populations. In this assessment of a case study, ¹ which sought to develop a collaborative framework through a partnership with Indigenous community leaders, the concepts of traditionally Western-informed knowledge systems have been examined in relation to the Indigenous knowledge systems in an attempt to provide a deeper understanding into the reasons why traditional research practices are unable to meaningfully address the problems faced by marginalized populations. An alternative approach to health research based on the principles of integrated knowledge translation has been examined by looking to the existing academic literature and relating the concepts back within the original case study in question. This assessment has

found that the related principles of knowledge user engagement and shared decision-making, when applied through the lens and values of integrated knowledge translation, can be effective in bringing about meaningful and lasting improvements to the health and wellbeing of vulnerable and historically marginalized communities.

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Integrated knowledge translation (IKT) in clinical practice guidelines development

A case note on:

Bashir NY, Moore JE, Tonelli M, Rodin R, Straus SE. Integrating evidence-based methods and knowledge user perspectives into guideline development and implementation. In: McCutcheon C, Kothari A, Graham ID, editors. How We Work Together: *The Integrated Knowledge Translation Research Network Casebook. Volume 1.* Ottawa: Integrated Knowledge Translation Research Network. 2019; p. 19-24. Available <a href="https://example.com/het-perspectives-based-methods-and-knowledge-based-methods-based-methods-and-knowledge-based-methods-based-

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SUMMARY OF CASE

The case titled "Integrating evidence-based methods and knowledge user perspectives into guideline development and implementation" primarily describes the knowledge translation (KT) approach utilized by the Canadian Task Force on Preventive Health Care (CTFPHC), an agency that develops and disseminates preventive healthcare guidelines for use in primary care across Canada.

The uptake of clinical practice guidelines among clinicians is low despite their evident ability to enhance clinical practice and patient outcomes. So, CTFPHC adopted Integrated Knowledge Translation (IKT) as a strategy to improve the uptake of guidelines. IKT primarily involved engagement with knowledge users throughout the process. The CTFPHC's KT Program at St. Michael's Hospital, the Public Health Agency of Canada (PHAC) and key knowledge users and their representative organizations facilitated the design and dissemination of CTFPHC guidelines. The annual evaluations indicated improved reach and uptake of CTFPHC guidelines. Moreover, several healthcare organizations changed their screening recommendations to align closely with CTFPHC guidelines. Knowledge users also rated their experiences positively.

Thus, the case describes how CTFPHC successfully incorporated IKT into its guideline development process. The approach described here can help enhance the relevance and applicability of guideline development in a variety of clinical areas through knowledge user engagement.

KNOWLEDGE TRANSLATION THEMES

Key knowledge translation themes derived from the case are as follows:

Integrated knowledge translation (IKT)

IKT, also known as research co-production, is an approach whereby researchers meaningfully engage with knowledge users. Ideally, knowledge user involvement begins early on in the project and they are

intimately involved throughout the project. In this case, CTFPHC used IKT as their approach to knowledge translation to increase the uptake of preventative care guidelines.

Structured knowledge user engagement

Knowledge users are individuals who can use or implement the research recommendations and/or findings. In this case, primary knowledge users are Canadian primary care practitioners and patients for whom guideline recommendations are intended, while secondary knowledge users are policy makers, health professional associations and researchers.

Role of facilitators

Facilitators are individuals who facilitate or catalyze the knowledge co-production process. These individuals function like formally designated knowledge brokers but may not possess this or a similar title. The role of facilitators in guiding and supporting knowledge users in the application of knowledge that has been conveyed to them is demonstrated in this case.

LEARNING GOALS

- 1. To learn about IKT as an approach to knowledge translation.
- 2. To learn about when, how and which knowledge users to engage with in a structured manner.
- 3. To learn about the role of KT facilitators in knowledge co-production.

ANALYSIS

Integrated knowledge translation (IKT)

IKT is an approach that involves meaningful collaboration between knowledge producers and knowledge users. It can be defined as "a model of collaborative research, where researchers work with knowledge users who identify a problem and have the authority to implement the research recommendations." The Canadian Institutes of Health Research (CIHR) views IKT as an approach whereby potential knowledge users are engaged throughout the research process, which is a unique feature of IKT. IKT has shown potential to increase the relevance, applicability and impact of research findings, which is broadly documented across an array of scientific literature.

In the context of this case, IKT was used as an approach to implement KT activities with the objective of increasing uptake of CTFPHC's preventative guidelines by clinicians in primary care practice across Canada. Engagement with primary knowledge users (patients and practitioners/clinicians) began from the very initial stages of the guideline development process. The CTFPHC also engaged with other end users, which will be elaborated in the second theme. The IKT approach adopted by CTFPHC was based on the knowledge-to-action (KTA) process model.⁵ The knowledge-to-action (KTA) framework proposed by Graham et al⁵ is among the most widely used frameworks to guide KT activities in Canada.

Developing clinical guidelines is a resource intensive task that can be wasteful if they are not utilized or if the recommendations within the guidelines are not adopted by practitioners into clinical practice. The evaluation of CTFPHC's guideline reach and uptake using an IKT approach showed promising results. The knowledge users who participated in CTFPHC's activities rated their experiences positively and expressed appreciation for the opportunity to contribute to Canadian healthcare. This certainly shows how

using an IKT approach, besides doing what it is primarily intended to do, can give a sense of ownership and accountability among the knowledge users towards the KT interventions/programs/tools.

These results are in line with a previous study that suggested that healthcare practitioners want their knowledge, perceptions, and beliefs heard, acknowledged, and implemented as part of the clinical practice guidelines development process. Similarly, a study that aimed to explore the determinants of clinical practice guideline use among neurologists suggested that end users of clinical practice guidelines should be included in the development process, as practitioners are more likely to adopt the guidelines into clinical practice if they were involved in their development. This study also supported the use of KT implementation strategies informed by a theoretical model such as the KTA framework and noted that doing so may improve the success of the strategy. However, using the KTA model does not necessarily lead to successful IKT if knowledge users are not truly involved in all steps.

IKT activities do take time and patience. It requires commitment from all parties involved because this process is mutually controlled. CTFPHC's program had a tangible product in the form of guidelines and infographics, which may have aided in measuring the effectiveness of the KT program. Cooke et al⁸ also emphasized that processes where participants can see the difference that they made or the contributions they put into the project is necessary for 'authentic' knowledge co-production. The case mentions that small knowledge user engagement may give rise to generalizability issues. One way to address this concern may be by involving different types of knowledge users and examining different levels of partnership.⁴ Nevertheless, there is limited published evidence on whether generalizability is a factor that needs to be considered when evaluating the effectiveness of IKT.

Structured engagement with the knowledge users

The Canadian Institutes of Health Research (CIHR) defines a knowledge user as "an individual who is likely to be able to use research results to make informed decisions about health policies, programs and/or practices." The process of engaging with knowledge users is complex but it is the most primary and essential component of knowledge translation. Specifically, in IKT, knowledge users are involved at every stage of the research and are essential, central, and equal contributors. Therefore, it is important to have an engagement strategy that has a well-defined structure and planned methods to ensure that knowledge users continue to engage throughout the process and meaningful input is obtained from them. Wensing and Grol¹⁰ suggested that well-structured approaches are needed in the integration of evidence and theory with end-user involvement. In other words, loosely defined unstructured approaches that do not define when, how and which knowledge users to engage with in a structured manner may not be successful in engaging knowledge users.

This case specifically mentions that knowledge users were initially only involved in usability testing of the KT tools, but overtime CTFPHC realized the importance of engaging knowledge users early on. Engaging with knowledge users early on helps to make the tools (preventative care guidelines in this case) more relevant and applicable to the users. Furthermore, a well-defined plan that outlines the stages to engage with the users aids in streamlining the process. CTFPHC engaged with the knowledge users in three different stages: when selecting outcomes to include in a guideline's systematic review protocol, when developing the guideline recommendations and when developing the guideline's KT tools. This

could be a practical representation of Boland et al's¹¹ study, which highlighted that each stage in the research process is an opportunity for collaboration with knowledge users.

The question of which knowledge users to engage with is as important as when to start the engagement process. In its guideline development process, CTFPHC engaged with primary knowledge users (practitioners and patients) as well as other end-users such as policy makers, health professional associations and researchers. Engaging with other end users worked as a supplement to the engagement of primary knowledge users and allowed the project team to get multiple perspectives. Primary knowledge users provide their experiential input to the guideline development whereas other policy makers, opinion leaders etc. can provide valuable input on real-world implementation issues and also help in the successful dissemination of the KT products on a wider scale. Involving a variety of direct and indirect knowledge users can lead to the production of high-quality knowledge tools that meet the requirements of all involved and facilitate timely integration into current practices.¹² This ultimately helps to improve the uptake of the KT products.

Face-to-face engagement with knowledge users is often cited as most effective in KT.^{12,13} CTFPHC's KT program collected knowledge user's input via interviews, focus group discussions, teleconferences, surveys etc. Research also suggests that interpersonal contact between knowledge creators and users can positively influence the uptake of clinical guideline utilization. A study that aimed to explore the determinants of clinical guidelines utilization in health ministries, regional health authorities and hospitals noted that the likelihood of guideline utilization is higher among those who participate frequently in conferences and workshops and have frequent person-to-person contacts with researchers in regional health authorities.¹⁴

It can be arguable that dictating when and how knowledge users and researchers need to collaborate for knowledge co-production is not pragmatic or practical. Similarly, the level of engagement of knowledge users, knowledge producers and facilitators throughout the KT process may also not be equal in real-world scenarios, but what matters the most is the quality of engagement.¹⁵ Therefore, having a structured, well-defined engagement strategy could be the key to maintain the quality of engagement.

Role of facilitators

KT strategies cannot by themselves overcome all barriers to the utilization of knowledge to improve patient care because it is a complex process. An external stimulus, prompting and support is often needed to support this process. ¹⁶ Facilitators are the individuals who act as external stimuli or catalysts for smooth delivery of KT activities. Harvey et al ¹⁷ described facilitators as individuals with the "appropriate roles, skills, and knowledge" ^(p. 579) to help move evidence into practice. They facilitate knowledge co-creation, knowledge synthesis, identification of barriers/opportunities, and development and dissemination of cogenerated KT tools/resources. According to Kitson and Harvey, ¹⁸ facilitation is the key ingredient that promotes successful implementation of knowledge into clinical practice. Facilitators can also mitigate the potential issues that can arise due to power imbalances between knowledge producers and users in the KT process. Overall, they have a vital role to play in enabling the successful translation of evidence into everyday clinical practice in order to provide effective care for patients. ¹⁹ Facilitators function like formally designated knowledge brokers but do not necessarily possess this or a similar title.

In the context of this case, CTFPHC had KT program staff at St. Michael's Hospital leading the implementation of KT activities targeting primary knowledge users. The establishment of a KT team responsible for developing an overall work plan and for carrying out ongoing monitoring is also supported by a previous study on KT. Lemire et al²⁰ suggested that having an active KT team makes it possible to conduct the process effectively and reorient it as needed. The KT program staff along with CTFPHC members and representatives from the PHAC coordinated and conducted key dissemination and implementation activities. The KT program staff worked synergistically with CTFPHC members, CTFPHC's evidence review and synthesis centres and scientific experts from the PHAC. Besides this, they facilitated the process by engaging these groups in developing materials, providing regular updates on the progress of the program and preparing a final report for each stage of the process, ultimately facilitating the uptake and impact of CTFPHC's guidelines. Primarily, this team functioned as full-fledged facilitators. The case does not specify whether anyone within this team had a designated title of "knowledge broker." However, knowledge brokers are also a type of "facilitators" who act as a bridge or link between knowledge producers and knowledge users.¹⁹

Several studies have aimed to identify facilitator characteristics associated with successful KT. An integrative review by Elledge et al²¹ explored the individual attributes needed to be an effective KT facilitator as described in previous research studies. This review grouped the desirable characteristics or attributes of effective facilitators into six main domains: self-awareness, self-management, social awareness, relationship management, skills, knowledge and understanding. Confident, flexible, intuitive, credible, empathetic, strategic, responsive, empowering, organized etc. were some of the desirable facilitator attributes listed across these domains. The study also noted that these attributes could be learned over time in the KT process. In clinical settings, understanding of these attributes may help the leadership to identify best-fit facilitators who can improve knowledge translation processes and, ultimately, improve patient outcomes. However, the study²¹ concluded that the extent to which any of these individual attributes contribute to facilitation is unknown as they have not been systematically evaluated. Further research is needed to shed light on this. On the contrary, perhaps, it may not be necessary to develop a specific set of attributes to define an effective facilitator since each facilitator can possess a unique set of attributes. A different set of facilitator attributes and skills might be needed in different types of settings. Nevertheless, persistence and commitment towards the KT goal would be most crucial and mutual to any set of attributes required to be an effective KT facilitator.

CONCLUSION

In summary, three major issues emerged from this case. Firstly, it reinforces the unique characteristics of IKT (i.e., IKT involves engaging knowledge users at the beginning of the project and keeping them intimately involved throughout the project). Secondly, it is particularly important to keep the knowledge user engagement processes and activities structured and planned. Engagement with primary knowledge users is crucial but IKT should not be limited to only engaging with primary knowledge users. Engagement with other knowledge users will allow capturing multiple perspectives. Finally, having committed facilitators in place ensures smooth management and coordination of KT activities.

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Integrated knowledge translation and chronic obstructive pulmonary disease

A case note on:

Sibbald SL, Verma JY, Rocker G. An INSPIRED story: How integrated knowledge translation is helping patients with complex chronic needs. In: McCutcheon C, Kothari A, Graham ID, editors. *How We Work Together: The Integrated Knowledge Translation Casebook. Volume 1.* Ottawa, ON: Integrated Knowledge Translation Research Network. 2019; p. 25-28. <u>Available here</u>.

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SUMMARY OF CASE

Chronic Obstructive Pulmonary Disease (COPD) is a complex lung disease that often results in impaired activities of daily living. Patients with COPD often require frequent and lengthy hospital visits to manage their condition, as well as associated comorbidities. To aid in the management of COPD patients' needs, improved models of care are warranted. The INSPIRED (Implementing a Novel and Supportive Program for Individualized Care for Patients and Families Living with Respiratory Disease) program was developed and implemented to address the broad spectrum of COPD patients' needs at the Queen Elizabeth II Health Sciences Centre in Halifax, Nova Scotia. The INSPIRED program's primary focus was to shift COPD care to the home through self-management, personalized action plans, and advanced care planning. Following success in Halifax, the INSPIRED program received funding from the Canadian Foundation for Healthcare Improvement (CFHI) and Boehringer Ingelheim Canada Ltd to expand the program across Canada.

To facilitate Canada-wide expansion, teams of patients, patients' families, researchers, practitioners, and industry professionals were brought together via an integrated knowledge translation (IKT) process. A quality improvement approach was adopted to guide the expansion and tailoring of evidence-based COPD care innovations to different Canadian locations. Team members participated in various IKT-related activities that included webinars, in-person workshops, and roundtable exchanges, which facilitated collaboration, knowledge exchange, and troubleshooting within and across teams. The INSPIRED program was adapted successfully to the majority of Canadian locations and improved several indices of COPD care for patients and families.

KNOWLEDGE TRANSLATION THEMES

The three knowledge translation (KT) themes evident in the INSPIRED case are related to **quality improvement** (**QI**), **knowledge brokers**, and **patient engagement**. The KT process utilized in the INSPIRED program was QI-based to address specific gaps in COPD care and to guide scaling up of the program from the initial location. QI experts took part in IKT activities such as roundtable meetings to

facilitate knowledge of QI initiatives and acquisition of QI-related skills by team members. The majority of team members reported not only the acquisition of QI-related skills, but also the implementation of QI-related skills in the design and scale up of INSPIRED innovations.

With respect to knowledge brokers, although the INSPIRED team was composed of several members (i.e., patients, families, researchers, practitioners, industry professionals, and QI experts), there was no explicit individual or organization acting as a knowledge broker. Based on the complex goals and challenges associated with the INSPIRED program, an individual or individuals acting as knowledge brokers may have facilitated the communication and capacity of team members.

The INSPIRED program engaged with patients and patients' families through involving them in the IKT activities. Specifically, patients and their families attended face-to-face workshops and webinars. Furthermore, patients and their families played a role in informing the curriculum and content delivery of the INSPIRED program, as well as the evaluation of the program post-implementation.

LEARNING GOALS

The three associated learning goals for the INSPIRED case are as follows:

- 1. Understand how to leverage QI principles within an IKT process.
- 2. Identify how a knowledge broker can promote the communication, capacity development, and organizational culture amongst team members.
- 3. Understand the role, value, and how to effectively facilitate patient engagement within an IKT process.

ANALYSIS

Quality improvement

The INSPIRED program utilized a QI approach to address complex COPD care challenges such as high use of hospital-based care and reduced quality of life. One QI-based strategy employed in the INSPIRED program was quality improvement collaboratives (QICs). QICs involve groups of professionals that support health care teams to apply evidence-based practices and QI strategies to improve the quality of health services. The theoretical underpinning of QICs is an iterative process in which collaboration of professionals facilitates the learning of evidence-based practices, driving changes in existing practices, followed by changes in patient outcomes, ultimately resulting in changes in health service use and/or costs. For instance, by addressing self-management of symptoms using evidence-based practices, this drove a change in existing COPD care (i.e., training and supporting patients to manage symptoms from home), which resulted in less emergency room visits and hospitalizations. Through the use of QICs, the INSPIRED program leveraged QI principles to shift COPD care to be more proactive.

Another important element of utilizing QI approaches is to first develop the QI capacity of team members. Taylor and colleagues outline that QI capacity involves "a deep understanding of and commitment to improvement to undertake ongoing, continuous work beyond any particular project." Furthermore, Taylor et al. stipulate three conditions required to develop QI capacity, which include: knowledge of QI approaches, knowledge of how to use data and feedback, and commitment of leadership and staff to dedicate time and resources to QI initiatives. The INSPIRED program hosted roundtable meetings with

QI experts, which facilitated the knowledge of QI approaches to team members. Furthermore, the involvement of QI experts promoted the development and implementation of QI skills by team members as demonstrated through an evaluation post-program in which acquisition of QI skills was reported by 76% of respondents. Regarding the allocation of time and resources to QI initiatives, team members dedicated significant amounts of time participating in roundtable meetings, face-to-face workshops, and webinars to develop QI capacity. Furthermore, funding from the CFHI and Boehringer Ingelheim Canada Ltd provided the resources necessary to support QI capacity development.

Although QI initiatives are often touted as being effective in improving health care services, not all QI initiatives share the same degree of success. Dixon-Woods and Martin outline several strategies to improve the effectiveness of QI initiatives.⁴ In particular they highlight that successful QI initiatives build capacity for designing and testing solutions as well as plan for scaling up from the start. The INSPIRED program built capacity for testing solutions through piloting the program at one health care setting first (Halifax). After studying the elements of the program that were both effective and ineffective, they were able to make adjustments prior to expansion. Moreover, they planned to scale up from the start and secured funding to be able to support the personnel and resources required to scale evidence-based and patient-centred innovations across different provinces. In this manner, the INSPIRED program leveraged QI principles within an IKT process.

Knowledge brokers

The INSPIRED team was composed of a diverse group of individuals, including patients, practitioners, QI experts, policy-makers, and industry professionals. The involvement of individuals with different knowledge bases, skills, experiences, and values can be challenging when working towards the development and scale up of a novel outreach program, such as INSPIRED. With this in mind, the inclusion of a knowledge broker as part of the INSPIRED team may have aided in the success of IKT activities. Knowledge brokers are instrumental in facilitating communication, knowledge sharing, and organizational change among stakeholders. Furthermore, knowledge brokers aid in developing and promoting the interactive process between researchers and decision makers. 6

For instance, an investigation conducted by Russell and colleagues evaluated the impact of using physiotherapists as knowledge brokers to improve the uptake of pediatric measurement tools in practice. One of the barriers to measurement tool uptake was the transfer of methodological and clinical expertise to practitioners at different practice sites. To facilitate this knowledge transfer, knowledge brokers were situated at each practice site as well as supported by a network of knowledge brokers that were trained by the research team. Through this model, practitioners at each site were supported and trained via their assigned knowledge broker on the methodological and clinical elements associated with the measurement tool. Ultimately, this knowledge broker network model resulted in increased knowledge and use of the measurement tool. The INSPIRED program could have benefitted from using a similar knowledge broker network model to ensure the communication of information and skills pertinent to delivering the COPD initiatives were clearly articulated. Furthermore, knowledge brokers can provide in-person assistance to resolve challenges in which remote communication cannot address. For instance, when issues with data collection support arose at certain INSPIRED sites, having a knowledge broker at each site would have

greatly improved the identification and eventual intervention of site-specific facilitators and barriers to data collection.

In several theories outlining the role of knowledge brokers, the idea of capacity building is brought forward. Ward, House, and Hamer suggest that capacity building can be viewed as "fostering self-reliance in both the researcher and the decision maker, developing the knowledge transfer and communication skills and developing the analytical and interpretive skills of the decision maker." In an investigation by Dobbins and colleagues, one-to-one interactions with knowledge brokers in a health care setting aided in facilitating evidence-based decision making by stakeholders. Thus, integrating knowledge brokers into the INSPIRED team could have promoted the development of team members' skills to interpret the COPD care-related data and ultimately use the findings to inform decisions for the program and its subsequent expansion.

Along with facilitating the capacity development of team members, knowledge brokers can also play a role in promoting organizational change. In a systematic review of the function and effectiveness of knowledge brokers in health-related settings, knowledge brokers were cited as facilitating organizational change by developing change management strategies, fostering receptivity among stakeholders, and encouraging decision makers to act as role models. A factor of organizational change that is important, particularly in health care settings, is organizational research culture. Organizational research culture can be defined as the value placed on research evidence in decision making. Knowledge brokers can improve organizational research culture by facilitating the access, use, and interpretation of research in the context of decision making. The inclusion of a knowledge broker as a part of the INSPIRED team could have aided in improving organizational research culture, ultimately supporting the ability of stakeholders to engage in evidence-based decision making.

Patient engagement

The INSPIRED program employed a "fully integrated and co-created KT approach" to promote the successful expansion and uptake of the program across Canada. IKT has been described as a model of collaborative research where researchers work with knowledge users who identify a problem and have the authority to implement the research recommendations. The knowledge users in the INSPIRED program were patients, patients' families, and practitioners involved in providing COPD care. A series of problems had been identified by the above knowledge users regarding current COPD care (i.e., frequent and lengthy visits to the emergency department, reduced quality of life). To address these problems, the INSPIRED program ensured patients and their families were involved in several IKT initiatives.

Patient engagement has been highlighted as an important aspect of the IKT approach. Patient engagement in research empowers patients and their families, increases trust between patients and practitioners, as well as improves the decision making process for both patients and practitioners. ^{13,14} Involving patients throughout the research process positively impacts study enrollment, data collection, and ultimately the relevance and uptake of research findings. ¹⁵ In the INSPIRED program, patients and their families attended virtual content webinars and face-to-face workshops, which promoted empowerment through gaining knowledge. Patients also played an active role in informing the INSPIRED curriculum and content delivery, increasing the relevance and uptake of the INSPIRED initiatives by program recipients.

Although the INSPIRED program took a few steps to involve patients, more strategies could have been employed to enhance the patient involvement in their IKT process. For instance, INVOLVE, a national advisory group in the United Kingdom funded by the National Institute for Health Research, provides several resources for researchers and research commissioners on how to facilitate patient involvement, such as engaging patients as early as possible in the development and prioritization of the research questions. ¹⁶ By consulting such resources that provide evidence-based strategies to involve patients in research, patient engagement is a more systematic process, ultimately improving the outcomes of patient outreach programs such as INSPIRED.

In a scoping review of patient engagement in Canadian health research, Manafo and colleagues identified several strategies to bolster patient engagement.¹⁵ For instance, they identified that "existing efforts to engage patients are often limited to preliminary activities that are not sustained across the research spectrum." When examining INSPIRED, it was unclear at what points of the IKT approach patients were involved and it seemed as though patients were involved in only specific activities (i.e., webinars, curriculum content and delivery). By ensuring patients are involved from the outset of the research program, in a wide range of activities, as well as in the evaluation of the program following implementation, overall quality of care is enhanced. Alongside sustained involvement of patients, Manafo and colleagues suggest patient engagement roles and duties should be clearly defined, a trusting and positive environment must be fostered, and recognition of patient contributions should occur.¹⁵ For instance, providing opportunities for patients to be co-authors on documents or co-presenters at conferences could be one way in which recognition of patient contributions is explicit. Through utilizing the aforementioned strategies, the effectiveness of patient engagement is improved, ultimately optimizing the quality of patient care.

CONCLUSION

In sum, the INSPIRED program leveraged quality improvement principles by forming QICs, developing QI capacity through improving knowledge, gaining commitment of team members to dedicate time and resources to QI initiatives, as well as planning for program scale up from the outset. INSPIRED could have seen greater success in the development and expansion of the program through the inclusion of knowledge brokers. Knowledge brokers could have aided in promoting the communication and capacity development of INSPIRED team members. Furthermore, the utilization of knowledge brokers may have bolstered elements of organizational structure, such as improving the organizational research culture of the program. Finally, although INSPIRED involved patients and their families in some of the IKT activities, a higher degree of patient engagement could have been achieved through involvement of patients throughout the entire trajectory of the program development, inclusion in a wider range of IKT activities, and explicit recognition of their contributions.

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The critical importance of knowledge translation in fostering an academicclinical partnership to redesign care on a pediatric inpatient unit

A case note on:

Cassidy C, Foley L, Rowe MB, Best S, Curran J. Fostering an academic-clinical partnership to redesign care on a pediatric inpatient unit. In: McCutcheon C, Kothari A, Graham ID, editors. *How We Work Together: The Integrated Knowledge Translation Casebook. Volume 1.* Ottawa, ON: Integrated Knowledge Translation Research Network;. 2019; p. 29-30. <u>Available here</u>.

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SUMMARY OF CASE

The Medical, Surgical and Neurosciences Unit (MSNU) of the IWK Health Centre in Halifax, Nova Scotia services approximately 2,000 pediatric patients per year. However, many of the children treated by this unit require highly acute care and more nursing resources than the centre is able to provide. As a result, a team from MSNU (consisting of the unit manager and two clinical nurse leaders) enrolled in a knowledge translation (KT) workshop series with the goals of: enhancing the research skills of clinicians and administrators, seeking guidance and support from a KT mentor and, ultimately, implementing a new high dependency care (HDC) model to improve the overall quality of care provided by the unit. This KT workshop marked the beginning of an 18-month collaborative partnership between the MSNU team and two KT mentors. Together, these partners conducted a problem analysis, a scoping review of existing literature and an assessment of the implementation barriers faced by all stakeholders. This preliminary work allowed the team to then design a study implementing and evaluating this HDC model on MSNU.¹ By involving a diverse team of professionals, this academic-clinical partnership was able to consider and incorporate various crucial viewpoints—the manager and clinicians offered their wealth of knowledge to ensure that the research questions and methods were relevant to the specific needs and culture of the MSNU, while the KT mentors offered their wealth of knowledge to ensure that the research approach was evidence-based. Many challenges were faced yet many benefits were reaped during this 18-month partnership. 1 Ultimately, this partnership led to a deeper appreciation for the importance of research and KT on MSNU.

KNOWLEDGE TRANSLATION THEMES

There were several important themes related to knowledge translation that emerged from this case study. First and foremost, the criticality of **integrated knowledge translation (IKT)** in redesigning patient care was highlighted. Redesigning an existing model of patient care is an overwhelming and complicated task; however, IKT can ease the process. IKT involves a collaborative research effort between the producers of knowledge and the users of knowledge so that all parties involved have a hand in shaping all phases of the

research process. This case study on MSNU perfectly exemplified the power that can come from treating knowledge producers and knowledge users as partners, how various strengths of stakeholders can add to the overall efficacy of a research/implementation team and how an IKT approach to research can lead to increased sustainability over time. By exploring this case note, it is my hope that readers will learn about the critical value that an IKT approach can harbour when addressing healthcare issues, with both academic and clinical implications, like the redesign of a patient care model.

Secondly, the theme of the potential power of **knowledge translation (KT) training and mentorship** arose from this case study. Although research exploring the importance of KT training and mentorship is still in its relative infancy, this case study perfectly exemplifies how prioritizing KT training and exploring KT mentorship can be beneficial in ensuring the success and sustainability of a KT intervention. This team involved with redesigning the MSNU's patient care model was first involved with a KT training program and then benefitted from the continued support of two KT mentors. Because of this KT training and mentorship, the team was able to build internal KT capacity, design an evidence-based research study and prove the worth of continuing to employ a KT research advocate even after the completion of the original study. By reading this case note, I hope that it becomes clear that KT training and/or KT mentorship programs are worth exploring and may be critical in ensuring that KT capacity is built among members of an IKT team.

Finally, the theme of **navigating various stakeholder roles and professional identity** while conducting IKT arose from this case study. Stakeholders are known to exhibit differing perspectives, expectations and values which can make collaborative work challenging. It is also possible that IKT may pose a threat to one's personal professional identity and values when one's expectations and perspectives are directly challenged by other stakeholders. The current case demonstrated varying needs from different partners/stakeholders in the case (especially in terms of research timelines) as well as personal professional identity challenges faced by the first author as she navigated filling multiple roles herself. It is my hope that through this case note, the reader learns about some of the challenges, yet ultimate benefits, associated with engaging multiple stakeholder roles in IKT.

ANALYSIS

Integrated knowledge translation

The first major, and overarching, theme emerging from this case was the crucial importance of IKT in redesigning patient care. Conducting research in a clinical setting is undoubtedly a complicated task. This task becomes even more complex when the research in question revolves around improving current practice or redesigning patient care. Within any realm of the healthcare field there is a wide array of professionals involved in a patient's care—each with specific and invaluable knowledge and expertise to offer. As a result, the relationship between those who produce and those who consume research must be carefully navigated.

The literature suggests that this relationship between producers and users should be viewed as a partnership, in which knowledge is co-produced rather than viewed as a linear process moving from production to use. It has been stated that this partnership will increase the relevance of the research being conducted as well as the likelihood of this research being effectively used.³ Although a variety of terms

exist to describe this co-production of knowledge, integrated knowledge translation (IKT) is among the most common, especially within the Canadian health sector.³ IKT, as described by Graham and Tetroe, "...involves collaboration between researchers and research users in the research process including the shaping of the research questions, deciding the methodology... [etc.]." The current case study on the MSNU involved a highly integrated team of clinicians, administrators and researchers/KT mentors—clinicians and managers who traditionally may have been viewed strictly as knowledge users and researchers who traditionally may have been viewed strictly as knowledge producers. This case study clearly acknowledges the different areas of expertise offered by the various team members—clinicians and managers who were able to offer insight into the specific context and culture of MSNU and researchers/KT mentors who were able to ensure that the issues under investigation were approached in an evidence-based manner. However, despite this acknowledgement of the various areas of expertise, the systematic KT research process, and subsequent study design to implement and evaluate the HDC model, involved all team members and remained true to the nature of IKT.

IKT has been recognized in the literature as an approach capable of leading to knowledge generation for improving health outcomes and healthcare delivery systems.⁵ The benefits stemming from the partnership explored in this case serve as a testament to the importance of IKT when redesigning patient care. It was reported that there were "relevant practice change questions and research findings" resulting from this 18-month partnership. The healthcare delivery system being investigated on MSNU was directly influenced by this IKT process in terms of research findings and the formation of important new research questions.

It has also been reported that the benefits resulting from an IKT process may extend beyond the immediate research project.⁶ Following the 18-month partnership reported on in the current case, the first author, Christine Cassidy, was asked to take on a new role as a part-time embedded nurse researcher on MSNU so that she, as one of the KT mentors in the case, could continue to provide research support. The value and benefits of Cassidy's work, and of this IKT approach in general, were clearly recognized and extended so that they may benefit other research endeavours in the future.

However, despite the impressive IKT partnership demonstrated in this case between clinicians, managers and KT mentors/researchers, there was one important party not included in the redesign of this pediatric inpatient unit—the patients themselves. Patients (and more realistically for a pediatric population, the caregivers of patients) are intimately involved in the healthcare process. Therefore, this population should also be intimately involved in the redesign-of-care process. According to Banner and colleagues, "recently, there has been a growing awareness of the need to include patients and members of the public within research processes," and that, "collectively, both IKT and patient engagement processes provide a vehicle to support research that can address health disparities and improve the delivery of effective and responsive healthcare services." It has been well-acknowledged that patient-oriented research approaches are an effective way to reflect the insights, and to acknowledge the priorities and needs of those who are most directly affected by the outcomes of health research—the patients. Therefore, it can be concluded that by involving the patients and caregivers in this collaborative case the impact and implications of HDC on MSNU may have been even more well-understood, refined and effective.

Training/mentorship programs in KT initiatives

The second theme emerging from this case study was the benefit of training programs and/or mentorship programs in KT initiatives. Funding agencies in Canada that support health research are becoming more and more focused on knowledge translation efforts. These funding agencies are not only looking to demonstrate accountability for the ways in which they spend public dollars, but importantly they are becoming gravely concerned with the gap that exists between the evidence generated during research endeavours and the application of this knowledge within the healthcare system.⁷ The barriers to the effective dissemination and use of research in healthcare are well-documented and include many factors like the sheer volume of research evidence that exists and continues to be produced, stakeholder access to research evidence, the time required to read research evidence and the skills required to appropriately appraise this evidence. To address some of these barriers, in 2012, Holmes, Scarrow and Schellenberg worked directly with a Canadian healthcare funding agency to propose a model assisting the agency in creating environments that are more conducive to KT. From this model, several important areas requiring attention were identified, including a need to build KT capacity. Importantly, this model acknowledged the complexity of using research evidence in a healthcare setting and how knowledge and evidence are conceptualized differently by various stakeholders consuming the research. As such, building KT capacity will need to look different as it is tailored to the specific needs, and gaps in knowledge, faced by individual stakeholders.

In 2014, Holmes and colleagues completed a provincial needs assessment to address the training needs of researchers and research users (in this case healthcare clinicians and decision makers) in order to more effectively build KT capacity.⁷ The results gathered from more than 1,200 survey respondents indicated that over 85 percent of participants were interested in furthering their skills in KT.⁷ Of these respondents, approximately 50 percent reported that they would require beginner-level training, while approximately 25 percent reported requiring more advanced training to supplement their existing knowledge.⁷

Unfortunately, despite clear awareness among the majority of participants of the personal need for KT training, more than 50 percent of respondents reported lacking the financial support and time to pursue such training. The partners from MSNU, including the manager of the unit and the two clinical nurse leaders who participated in the KT training program, serve as a great example of a team that valued the importance of KT training and were able to successfully secure both the time and the funds to expose their team to KT training and KT mentorship. The benefits of this training can be directly seen in the success of their KT research process and by their sustained KT research support on the unit following their original partnership. In the success of the support of the unit following their original partnership.

Many KT training programs currently exist, often aiming to prepare researchers to conduct KT research projects or to secure KT grant funding. The KT workshop series that was attended by the partners of MSNU in the current case was no different. This workshop was described as being, "designed to strengthen clinicians' and administrators' research skills for designing a practice/policy change with support from a KT mentor." However, as Park and colleagues stated, "there is a need to build capacity among those responsible for KT practice so that clinical interventions are optimally implemented to improve patient outcomes." The team from MSNU included nurse leaders who would have brought clinical expertise with them to the training session. However, it was mentioned that the overarching goal

of attending these KT training sessions was to enhance research skills to better implement and evaluate the new HDC program on MSNU. It likely would have been beneficial to also provide KT training for the other nurses and clinicians working within the unit to aid with implementation efforts. Redesigning patient care is undoubtedly a complex process and it is important to ensure that KT is prioritized by all partners involved—especially those on the front lines of continuous patient care who are often excluded from training processes that target those in more classic leadership roles.

One approach to ensuring that a greater number of healthcare professionals are exposed to KT training is to provide mentorship programs, much like that described in the current case study. The team from MSNU worked with both a junior and senior KT mentor throughout their 18-month partnership. Mentorship has been shown to be an effective training strategy that may be used to develop KT capacity and train clinicians. In a series of interviews conducted with Canadian researchers and research users, participants expressed uniform interest in a mentorship program over other types of KT learning opportunities because they felt it would allow for tailored and credible information to be provided when needed. Interestingly, participants opinions varied on whether these mentors should be internal or external and whether they should be KT experts or clinical experts with KT experience and training. Although the research pertaining to KT mentorship programs is still in its relative infancy within the literature, the current case study provides a strong example of the success of one type of mentorship program and, more generally, demonstrates how effective mentorship programs can be in providing integrated teams with dedicated and tailored KT direction and knowledge. The support exhibited by the KT mentors in this particular case ensured that the redesign of the patient care model was conducted in an evidence-based manner.

Although KT training for researchers has been demonstrated in a variety of case studies, training for research users has been less well documented. In addition to a general lack of literature regarding training for these research users, existing training initiatives focusing on KT practice have not been sufficiently evaluated to date. Park and colleagues attempted to address this lack of rigorous evaluation by conducting a longitudinal investigation of the KT training initiative entitled "Foundations in KT." This program involved three tailored-to-knowledge-users in-person workshops, coaching and an online platform to allow for continued training and knowledge exchange between participants. As a result of this training program, participants' self-advocacy in KT activities and participants' ability to use evidence to inform practice significantly increased over time. Additionally, outcomes from this program illustrated an increased understanding and confidence in using KT, as well as greater achievement of individual KT project objectives, planning and problem solving. These positive participant outcomes were also judged to have been sustained 24 months after completion of the training program. Although more research is needed to further explore the nature and effectiveness of both KT training and mentorship programs, the current case can be combined with the existing literature to suggest that KT training and mentorship may be a critically important aspect of successful KT interventions.

Managing stakeholders

A third major theme that emerged in the description of this case study were the challenges associated with managing various stakeholder roles during the IKT process. In the current case, the first author shared her struggle with navigating her own professional identity and role as both a nurse and a researcher who then

took on a KT mentorship role. She stated that, "I often struggle with my professional identity; my clinical and academic colleagues assign vastly different values on research and clinical practice." Collaboration between various stakeholders is of crucial importance in IKT research but is also extremely challenging because of the various roles the stakeholders play - this problem is further complicated when one individual is fulfilling multiple roles similar to the first author in this case.

Of course, "collaboration between researchers and decision-makers may reveal differing perspectives, expectations, and values, leading to greater understanding and improved communication, which creates trust and a shared vision that enable more effective and sustained partnership..."¹² However, it is also possible that IKT may pose a threat to one's professional identity and values when expectations and perspectives are challenged by other stakeholders. It is possible that, in some cases, IKT may be avoided entirely due to an inability to overcome the challenges associated with coordinating the complex, and sometimes conflicting, initiatives of stakeholders who all hold different views and are pursuing various interests.³ At a very basic level, researchers and research users, whether that be policymakers, managers, practitioners, etc., come from very distinct worlds and cultures. 13 These different stakeholders are known to hold, "different values, timelines, goals and rewards." The current case study mentioned that the differences in priorities that existed between various stakeholders was a primary barrier they faced during their study. They stated that there were, "differences in priorities, especially with regards to timelines. We experienced pressures to implement practice changes quickly, but a rigorous KT research process required time to collect and analyze data." This statement emphasizes the theme of navigating complex and differing stakeholder roles - even at a basic level of navigating timelines there were challenges experienced. This is just one example of different priorities in research - those who place the upmost value on quick research results and those who place the upmost value on a rigorous and thorough research processes.

To help to mitigate the challenges associated with these various stakeholder roles in IKT projects, some studies have advocated for the use of an intermediary agent, sometimes referred to as a knowledge broker. Knowledge brokers work to identify, engage and connect various stakeholders, facilitate collaboration between different partners, and support continuous information sharing and communication, among other roles. It may have been beneficial, for all parties involved in the MSNU study, to engage a knowledge broker to mitigate the differences in priorities between stakeholders. This benefit would have been especially great for the first author who found herself struggling with her personal identity while attempting to balance more than one role in the current study. No matter how challenging it may be to navigate varying stakeholder roles in IKT, it is known that "an IKT process builds the capacity of researchers and knowledge users to value each other's perspective, but more importantly, the process makes space for an additional, "value-added", communal perspective." Navigating the challenges inherent to an IKT process involving different stakeholders is important and beneficial to research overall. This particular case study certainly benefitted from the expertise and clinical context awareness of the MSNU clinicians and manager as well as the evidence-based knowledge provided by the researchers/KT mentors in addressing their practice issues of redesigning care.

CONCLUSION

This case study emphasized several important KT themes that should be considered by any researchers conducting IKT research. First and foremost, the criticality of the IKT approach in redesigning patient care was highlighted in this study. Engaging both knowledge producers and knowledge users (in this case clinicians, managers and researchers/KT mentors) to work as partners in creating and implementing a study allows for both clinical and academic benefits when working to redesign a healthcare model. Secondly, the theme of the potential power in knowledge translation (KT) training and mentorship arose. This case perfectly exemplified how prioritizing KT training and exploring KT mentorship can be beneficial in ensuring the immediate success and longer-term sustainability of a KT intervention—two factors that are exceptionally important when considering healthcare interventions like the redesign of a patient care model. Finally, the theme of navigating various stakeholder roles and professional identity while conducting IKT was explored. Stakeholders have proven to exhibit differing perspectives, expectations and values, which can make collaborative work challenging. It is, however, also known that the benefits resulting from the engagement of multiple stakeholders' views and talents make navigating the challenge ultimately worth it. The themes explored in this case study reflect truths that exist across the knowledge translation in healthcare research field and should be considered by all researchers embarking upon an IKT journey.

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Action against malnutrition

A case note on:

Coates E, Hasselback P. From coalition to action plan: Addressing malnutrition in older adults through IKT. In: McCutcheon C, Kothari A, Graham ID, editors. *How We Work Together: The Integrated Knowledge Translation Research Network Casebook. Volume 1.* Ottawa: Integrated Knowledge Translation Research Network. 2019; p. 31-33. Available <a href="https://example.com/here/beach-back-nowledge-

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SUMMARY OF CASE

Up to one out of every two older adults in Canada is at risk of malnutrition, yet there exists a substantial gap in the delivery of malnutrition care for older adults. To address the issue of older adult malnutrition on Vancouver Island, a team of researchers along with Dr. Hasselback and Erin Coates, both members of the Vancouver Island Health Authority, developed local Integrated Knowledge Translation (IKT) activities and a Malnutrition Coalition. The IKT activities consisted of sharing evidence to inform health system and practice; discussing barriers and resources available to support practice change; and increasing involvement of community partners, clinicians, and decision-makers in research partnerships. The greatest challenge identified when promoting these IKT activities was time. The involvement of multiple coalition partners is often challenging as most partners have numerous competing priorities and limited time, thereby hindering the in-depth sharing of ideas.¹

KNOWLEDGE TRANSLATION THEMES

The three knowledge translation (KT) themes identified in this case are:

- 1. Collaboration amongst researchers and users;
- 2. The role of champions in the success of KT interventions; and
- 3. The utilization of an IKT approach.

To effectively collaborate amongst researchers and users, a collaborative research design must be in place to successfully capture the needs of both parties. There are three components to consider when creating a collaborative research design: (1) identify issues important to both the researchers and users, (2) transform these issues into a feasible research [goal], and (3) choose appropriate and feasible priorities for the project.² In relation to this case, it was apparent that researchers, clinicians, and community partners have a common goal of addressing malnutrition in older adults, and they have collaborated and created appropriate, feasible projects to address the issue at hand by forming the Malnutrition Coalition, hosting workshops and creating an Action Plan.

Champions, defined as leaders who are instrumental in facilitating and improving communication and knowledge sharing among key stakeholders, are vital for the success of KT interventions.³ Two types of champions are identified through the literature: project change champions, those who serve as a point person for a project and help enhance their team's quality improvement efforts; and organizational change champions, those who support not only the specific change efforts of a project but also provide long-term support for ongoing improvement.⁴ In this case study, there were numerous project change champions such as healthcare professionals (nurses, dieticians, Medical Health officers); University associates (Gerontology professors, research associates, and Adjunct Faculty members); members of community organizations (Seniors organizations, members of nutrition-based organizations, Canadian Malnutrition Task Force, Nanaimo Aboriginal Center); and government members (Nanaimo Municipality Social Planner, Health Living & Health Promotion Branch of Population & Public Health B.C. Ministry of Health).¹ The role of facilitating continuous, ongoing collaboration for the malnutrition project will be assumed by project change champions, who in this case study was identified to be the initial vocal advocates, Erin Coates and Dr. Hasselback, who will continue to facilitate ongoing discussion with partners and engage leaders to receive continuous support for the program.

Lastly, integrated knowledge translation (IKT) was the third theme identified in this case study. IKT is a process in which there is an ongoing relationship between researchers and decision-makers for the purpose of engaging in a mutually beneficial research project or program of research to support decision making.⁵ Both researchers and decision-makers benefit from utilizing an IKT approach, and such proposed benefits include the ability to gain a greater understanding of the policy or practice environment and gain a broader reflection of one's own activities.⁵ However, there are also several challenges that can occur by utilizing an IKT approach such as the inability to coordinate complex initiatives, lack of incentives for researchers and decision-makers and the delicate balance of power, politics and perceptions.⁵ In this case, an IKT approach was effectively utilized as multiple stakeholders and researchers were able to effectively engage and collaboratively create action plans to address malnutrition in older adults.

LEARNING GOALS

The three learning goals for this case study are:

- 1. Understand how to identify issues important to researchers and users to create a collaborative research design;
- 2. Identify the importance of project champions and organizational change champions; and
- 3. Understand and effectively use an integrated knowledge translation approach in KT interventions.

ANALYSIS

Collaboration amongst researchers and users

Partnerships are "collaborative relationships between two or more parties that have agreed to work together, that is based on trust, equality and mutual understanding, and focuses on the pursuit of common goals that cannot be accomplished by the partners on their own." There is great emphasis placed upon this collaborative relationship amongst researchers and knowledge users as it could improve the use of research results in policy decisions and practice settings. ^{6,7}

In order to achieve the desirable outcome of an intervention, the literature identifies the need for a dialogue amongst partners, in order to transform tacit knowledge into explicit knowledge, both internally and externally. In doing so, a collective agreement is maintained amongst all of the parties. However, this utopian cooperation amongst parties is often hard to achieve as members are sometimes not fully dedicated to a project or do not recognize any inherent benefit or reward. Lam and Lambermont-Ford emphasize this behavior in knowledge sharing theories, stating that much of the theory is based upon assumptions of harmonious cooperation amongst parties without the need to be rewarded. The lack of motivation and reward is one of the most prominent factors in creating and sharing knowledge but is often overlooked in the literature, as much of the focus is placed upon leveling the power and politics dynamics amongst groups. Though these dynamics are important to consider when creating collaborations, the factor of motivation and reward must also be considered, as the lack of reward can lead to decreased self-determination of partners, thereby hindering the implementation of the intervention. The approach used in the implementation of an intervention can greatly impact an individual's reaction to a new practice. Therefore, it is considered vital for all partners to be motivated and be committed to a project for a successful implementation.

To maintain motivation in the implementation of an intervention, it is important to consider creating a collaborative research design in which the desires of researchers and knowledge users can be established by creating a design that addresses the needs of both parties.² Three principles are necessary to consider when creating this design: identifying issues important to both the researcher and knowledge users, operationalizing these issues into a feasible research question and choosing appropriate, clear and feasible priorities for the project.² During this period, it is vital that both parties do not force each other's agendas upon one another; rather, a collaborative effort must be taken in order to incorporate the researchers' interests and the needs identified by the knowledge users, who will ultimately be using the results of the research in practice.² There are key skills identified that will lead to successful collaboration amongst partners which include: being an active listener, recognizing the value of every individual's expertise, being flexible to move beyond initial ideas, and providing every individual an opportunity to voice their opinion.² Once the issues have been identified by each partner, they must work collaboratively together to transform the issues into a feasible research project.² At this stage, the researchers' scientific background is particularly valuable as they have the ability to introduce other partners to the scientific method; an exchange of knowledge between researchers and knowledge users at this stage will allow questions to be developed that reflect the needs of partners, with the scientific rigor required for research.² Lastly, partners must set feasible and realistic priorities for the project at hand.² The motivation to complete a project can easily diminish if the project does not have any real benefits to the knowledge users or researchers, if it does not have support from the users and researchers involved, if there are too many barriers to sufficiently overcome and if there is a lack of clarity regarding the time frame of the project. To maintain and ensure the motivation of partners exist throughout and after the implementation of a project, extensive discussions must occur amongst all partners to ensure everyone's priorities and needs are being sufficiently met.

The formation of the Malnutrition Coalition and the drafting of the malnutrition Action Plan, demonstrated a great collaborative and consultative effort employed by all of the partners involved.

Such partners included healthcare professionals (nurses, dieticians, Medical Health officers); University associates (Gerontology professors, research associates, and Adjunct Faculty members); members of community organizations (Seniors organizations, members of nutrition-based organizations, Canadian Malnutrition Task Force, Nanaimo Aboriginal Center); and government members (Nanaimo Municipality Social Planner, Health Living & Health Promotion Branch of Population & Public Health B.C. Ministry of Health). The Malnutrition Coalition represented a significant collaborative effort, involving an interdisciplinary team for creating policies to address malnutrition in older adults, creating action plans to highlight the physical, mental, social and emotional impacts of malnutrition, sharing national and international best practices, developing recommendations for improving health surveillance amongst older adults, and using a variety of dissemination strategies (workshops, conferences) to reach diverse audiences. This collaborative effort was successful as the findings and recommendations created from the coalition and action plans led to a significant uptake by partners such as practitioners, policy makers, and researchers.

The role of champions

The second theme identified in this case study was the role of champions in the success of KT interventions. As defined by Howell and Higgins, champions are individuals who actively and enthusiastically promote an innovation to others for the good of the organization. Champions identify with an idea as their own, emphasizing the personal commitment they have towards the role, as opposed to reflecting expertise or seniority. Rather, champions promote the innovation to organizational members by acting as a "boundary spanner" between head management and other team members.

The success of champions is reliant upon three critical factors which include: expressing enthusiasm and confidence about the innovation, getting the right partners involved in the project, and persisting under any adversity. With the increasing demand to transform healthcare practices, the presence of a champion is said to be vital in driving this transformation as they can aid in the implementation of a vast range of change initiatives in healthcare practices. 12

Two types of champions are identified in the literature: project change champions and organizational change champions.⁴ Project change champions are identified as individuals who serve as the point person for the project and help enhance their team's quality improvement efforts.⁴ Organizational change champions are distinguishable from project change champions as they support not only the specific change effort for the project, but offer long-term support for ongoing improvement.⁴

In this case study, it was evident that there were project change champions and organizational change champions who were successful in implementing and sustaining their change roles. The two founders of the Malnutrition Coalition, Erin Coates and Dr. Hasselback, were identified to be the organizational change champions who had initiated the project and IKT activities, had articulated a clear vision to implement ongoing IKT activities for malnutrition awareness and prevention and garnered support from various stakeholders to enact that promising vision. Both organizational change champions were very active in the early stages of the project by providing practice change ideas, hosting preliminary workshops, identifying partners relevant to the project, engaging in follow up discussions and gaining

support for ongoing collaboration.

The project change champions in this case can be identified as healthcare professionals, academia associates, community and government members who chose to participate in the IKT workshop initiatives as well as the Malnutrition Coalition. This case study did not explicitly mention the degree of the project change champions involvement in the initiatives but it can be inferred that the heavy involvement from the organizational change champions motivated these champions to take ownership and responsibility of implementing IKT initiatives in their practices.

Initiatives that do not employ either project change champions or organizational change champions have been identified to have lower success rates as opposed to initiatives that do.⁴ This result is evident in a case initiative called EPIC (Enhancing Practice, Improving Care) where the quality improvement trial was aimed at improving diabetes and depression care in primary care settings.⁴ In one of the practice settings in which this initiative was employed, EPIC-related initiatives (tracking systems and improvement team meetings) were quickly abandoned due to the lack of employing project change champions or organizational change champions.⁴ This was due to an absence of enthusiasm as members of the practice did not show any initiative in promoting the intervention or express any vision for practice improvement.⁴

The results of this study, as well as the literature, have identified the need for champions in the success of implementing KT initiatives. A project champion can be utilized in interventions if the goal is to solely accomplish incremental, project-based interventions during a set time frame. However, if the goal is to have sustained practice change, then an organizational change champion is vital to the intervention as they provide leadership, authority and continuous ongoing support for an intervention.

Using an IKT approach

Lastly, the third theme identified in this case study, is the utilization of an integrated knowledge translation approach. As defined by Gagliardi et al,⁵ integrated knowledge translation (IKT) is the ongoing relationship between researchers and decision-makers for the purpose of engaging in a mutually beneficial research project or program of research to support decision-making.

Theoretically, IKT is similar to community based participatory research as both methods have a shared desire to co-create knowledge, both methods "accept" different forms of knowledge by negotiating perspectives between researchers and knowledge users and both methods blur the distinction between researchers and participants. ¹³ Important principles that define community based participatory research can be applied to KT approaches such as techniques for working together, structures that support harmonious collaboration, dynamics of relationships and processes for working together. ¹³ In theory these approaches may seem similar; however, participatory research methods are mainly used to promote community driven solutions, whereas IKT is used to produce research-based solutions and knowledge users are heavily involved as they have the ability to promote change after research completion. ¹³

The collaboration amongst researchers and knowledge users are heavily promoted as it has the potential to improve the uptake of research results in policy decisions and practice settings.⁶ Benefits of involving

decision makers in the research process include: enhancing knowledge and skills, gaining a broadened reflection on their own activities, having the ability to ask researchers relevant questions, and gaining new contacts with other researchers and decision makers.^{5,6} Researchers benefit from this frequent collaboration as it allows them to develop research questions that are relevant to political priorities and contextual opportunities, in addition to gaining a greater understanding of the decision-making context.⁶

An IKT initiative that is performed well has the ability to improve the performance of health systems as IKT encourages collaboration, dynamic research and engagement amongst different partners.¹⁴ Furthermore, IKT has the ability to support the uptake of research into policy as it enhances communication, trust and a shared vision amongst partners.¹⁴ However, an IKT approach can be challenging and can produce unfavorable results due to factors such as the failure to overcome differences, lack of funding or incentives, incorporating diverse stakeholders, power imbalances and political differences.⁵

In the Coalition to Action Plan case study, it was evident that an effective IKT approach was utilized amongst the researchers and the diverse group of knowledge users from clinical practices, community-based programs, universities and government settings. In this case, these knowledge users were involved in the development of the Malnutrition Coalition and workshop initiatives addressing malnutrition. To have a successful collaboration amongst a diverse group of stakeholders, it can be assumed that there was a significant amount of trust and time invested into harboring these relationships, as it requires sustained effort and commitment by all of the partners involved, as indicated in the literature.¹⁵

CONCLUSION

In conclusion, when working collaboratively with other partners, it is necessary to identify issues that are important to both the researchers and users, operationalize these issues into a feasible research question and choose appropriate, clear and feasible priorities for the project at hand to create a successful collaborative research design. Furthermore, project and organizational change champions are valuable for KT interventions; to have long-term sustainability of an intervention, an organizational change champion should be employed. Lastly, by utilizing an IKT approach, successful collaborations can result amongst all stakeholders, which can lead to the successful implementation of an intervention.

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Analyzing the use of integrated knowledge translation during the implementation of a shared decision-making initiative: A case note

A case note on:

Boland L, Shephard A, Lawson M. Implementing shared decision-making in pediatrics: Spotlight on integrated knowledge translation. In: McCutcheon C, Kothari A, Graham ID, editors. *How We Work Together: The Integrated Knowledge Translation Research Network Casebook. Volume 1.* Ottawa: Integrated Knowledge Translation Research Network. 2019; p. 34-39. Available <a href="https://example.com/here/beach-molecules/be

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SUMMARY OF CASE

The use of shared decision-making (SDM) plays a key role in enabling patients and their loved ones to autonomously make health-related decisions. The case *Implementing Shared Decision-Making in Pediatrics: Spotlight on Integrated Knowledge Translation*, authored by Laura Boland, Allyson Shephard and Margaret Lawson, details the journey of an integrated knowledge translation (IKT) approach to increasingly utilize SDM at an Ottawa hospital.²

Noting that the use of SDM is limited in pediatric settings, an implementation team at the Children's Hospital of Eastern Ontario (CHEO) utilized IKT to roll out an SDM program in their pediatric unit.² This team consisted of Boland, a doctoral candidate, Shephard and Lawson, both knowledge users at the hospital, as well as the Vice President (VP) of Patient Services, the decision-maker in this case. The IKT activities taken up included presenting the program to the knowledge user's management team to ensure support, regular communication through quarterly meetings, and the consultation of other knowledge users, such as healthcare providers, children and parents.² The team also utilized the Knowledge-to-Action (KTA) framework to guide implementation, which meant that it was based on research evidence and steps such as barrier assessments, training for healthcare professionals and onsite support were taken.²

The program appeared to have many successes, notably that pilot testing showed parents and youth found the program feasible and it reduced decisional conflict.² Alternatively, a survey revealed that 52% of healthcare professionals at CHEO are still not using SDM.² The program also suffered after the unexpected departure of the VP of Patient Services, as the team was unable to make an equally strong partnership.² Overall, this case brings forward several important IKT considerations for implementation that will be analyzed in this case note.

KNOWLEDGE TRANSLATION THEMES

This case note will analyze the following knowledge translation (KT) themes related to the case:

Barriers & facilitators of IKT

The use of IKT has been suggested as an approach to enhance the facilitation of evidence-based practice through partnerships between research producers and knowledge users.³ In this case, the implementation team utilized various IKT activities, such as regular meetings with knowledge users and securing the support of management. While these benefitted the SDM program, other IKT activities may have been taken to facilitate success of the program. This theme will turn to literature to understand factors that influence success of IKT approaches with the goal of providing suggestions to further improve implementation at CHEO.

Reframing "expertise"

Utilizing IKT approaches can help facilitate the process of expanding how we define 'expertise.' Traditionally, researchers and healthcare providers are considered primary knowledge generators. However, it is suggested that including such tacit knowledge helps healthcare providers to provide patient-centered care – the ultimate goal of SDM.⁴ In this case, the implementation team consulted with key knowledge users, such as parents and their children, and utilized this feedback during implementation. The exploration of this KT theme through literature will discuss how to better facilitate input from patients.

Sustainability of KT interventions

It is important to ensure the long-term success of programs so that resources are maximized, long-term outcomes are achieved, and positive changes are sustained.⁵ This case revealed that KT interventions may be susceptible to temporality. More specifically, due to the unexpected departure of a senior decision-maker on the implementation team, the sustainability of the SDM program suffered. This theme will explore what the KT literature says about how we can make KT initiatives more sustainable so that they have a continuous impact.

LEARNING GOALS

In order to help articulate the purpose of this case note, learning goals will be used to describe the knowledge the reader will gain from the subsequent analysis. Upon completion of reading this case note, the reader should be able to answer the following questions related to each KT theme discussed in the previous section:

- 1. What factors influence the success of integrated knowledge translation approaches?
- 2. How do we effectively facilitate the process of including expertise of patients in research and decision-making?
- 3. What strategies might be used to help ensure that KT initiatives are sustained and have long-term success?

ANALYSIS

Barriers & facilitators of IKT

Literature such as that of Funabashi, Warren and Kawchuk examined key barriers and facilitators to KT approaches. In their work, they found that clinicians often do not have complete information and specific details of the KT intervention to engage with it, despite their will to do so.⁶ These findings are relevant to this case, as an identified issue was that 52% of healthcare professionals at CHEO are still not using SDM and only 32% are using it occasionally.² With this literature in mind, the implementation team should take steps to ensure healthcare providers who are meant to be utilizing SDM with their patients have all the necessary details of the intervention to execute it appropriately. The authors of the case did outline that training was provided through a PowerPoint presentation to providers and families, so this likely has implications for the method of training that was provided to healthcare providers.

In the same vein, Funabashi, Warren and Kawchuk go on to identify that a barrier described in literature was the inability of clinicians to apply research knowledge. This is reinforced by authors Preyde and colleagues when they state that a main challenge of IKT is the limited research knowledge of knowledge users, as it has been reported that they struggle to apply research evidence. Therefore, to increase the utilization of evidence-based SDM by healthcare providers, training should be given to providers when actually consulting with patients, as it may be difficult to translate knowledge presented in a PowerPoint into practice.

Another barrier commonly experienced throughout IKT approaches is the lack of knowledge by investigators or implementers on the actual day-to-day activities within the clinical setting.⁷ This has resulted in negative implications for the feasibility of initiatives given that there is a lack of intimate knowledge on daily operations and protocols.⁷ In this case, there was no mention of steps that the implementation team took to experience what healthcare providers went through when assisting families with the decision-making process. They noted that they received feedback throughout implementation, but this is inherently different from obtaining intimate knowledge of day-to-day life in the clinical setting. The way the SDM program was designed and provided to healthcare providers may have increased uptake if the implementation team gains an understanding of providers' daily challenges and realities.

Literature exploring barriers and facilitators of IKT was thoroughly summarized by Gagliardi and colleagues who conducted a scoping review to highlight 9 enablers and 15 barriers of IKT.³ Examples of enablers included leadership, training and mentoring, and performance incentives, while some barriers were time available for IKT, differing values, and lack of resources or funds.³ Further, they found multiple knowledge gaps, such as the fact that there is a lack of description of the underlying theory or logic that guides the IKT approach and that IKT activities often involved meetings, but not the nature or level of engagement of these meetings.³ These findings can be presented alongside the work of Kreindler, who proposes a realist approach to evaluate implementation. This is a systematic way to understand the causal pathway between intervention and desired outcomes. This means while it is useful to identify barriers, it is equally important to actually identify where each is located in the causal chain.

In the context of this case, a barrier reported by Gagliardi and colleagues that is experienced by the CHEO implementation team is regularity of decision-maker participation in activities, as well as the knowledge

gap that the nature of decision-maker involvement is unknown.³ The case articulates that communication occurred through regular quarterly meetings and that they collaborated on aspects of implementation such as program design and outcome evaluation and dissemination,² but questions still remain around how much engagement there actually was from key decision-makers on the implementation team, such as the VP of Patient Services. Identifying that this barrier likely is being experienced at several points in the causal pathway emphasizes that it is important to address. Literature suggests that having strong partnerships with decision-makers at multiple points improves the success of IKT initiatives,⁹ but more is needed to understand what this partnership actually looks like. To lend more credibility to the IKT approach used in this case and provide more transferable knowledge for similar cases, there should be a better articulation of the extent to which decision-makers were engaged and participated in the implementation and decision-making process of the SDM program.

Reframing "expertise"

KT literature often challenges the definition of 'expertise' by prompting researchers and healthcare providers to include other types of knowledge, such as patient preferences and personal experience. Further, there is evidence that suggests tacit knowledge is utilized even more than explicit knowledge in practice when implementing programs and that the success of studies are often influenced by the level of patient involvement. While we have evidence that suggests it is important to utilize the broadened definition of 'expertise', it is also important to understand how this process can be appropriately facilitated.

The first example to be highlighted to reinforce inclusion of patient feedback is one by Liddy and colleagues, who utilized an IKT strategy to support the expansion of regional electronic consultation.¹⁴ This is a similar strategy to the one utilized in this case, as both relied on IKT to guide the collection of various types of knowledge. To gather perspectives, Liddy and colleagues relied on a strategy based on five key activities, one of which being "including patient voices." Liddy and colleagues partnered with a volunteer network to recruit patient advisors who participated in multiple discussions on ways that their policies could ensure it delivers high-quality and patient-centered care. Once feedback was collected, the authors communicated it back to patients to ensure that it was properly understood, stating that this process largely shaped actionable suggestions. In the case at CHEO, patients (and their families) were consulted by receiving knowledge on the importance of SDM, then providing feedback through an iterative process. The implementation team broadly states that feedback was gathered from children and families, but it is unknown how this feedback was taken into consideration during decision-making. To better facilitate the process of including patients' voices, the implementation team should communicate how patient input is being used back to patients.

Another key piece of literature that shares insight on the facilitation of patient voices in research is that of Shippee and colleagues, who conducted a systematic review to understand patient and service user engagement. They found that in-person activities led to higher knowledge user engagement and that having patients hold a more active participatory role strengthened the research. Further, the authors presented the Patient Engagement Evaluation Tool (PEET) to help determine how engaged knowledge users were in the research process. This means that a key part of collecting patient input is how this is logistically done. In this case, families were given surveys to provide feedback after engaging with the

SDM program and given postage paid envelopes to return them by mail within two weeks. ¹⁶ Literature reflects that this may not be an effective way to engage these key knowledge users, and that this process could have been improved by consulting with families in-person about their experience and ensuring they are more active in the implementation process. Further, the availability of tools such as the PEET could have been useful for the implementation team at CHEO to evaluate how children and families were engaged in the process, as they are arguably one of the most important knowledge users in this case.

While there is a lot of available information on ways to engage in collecting patient input through research and decision-making, gaps remain in the literature. More specifically, there is a disconnect in the approaches utilized across the literature, and there is a clear need for a standard framework for this process. ^{17,18} This could be one of the reasons that patient input was not suitably collected in this case. With the growth of this body of academic literature over time, however, more standardized recommendations and frameworks may help to solidify proper and effective ways to collect and utilize patient input in KT initiatives. In the meantime, resources in Canada such as the Strategy for Patient-Oriented Research (SPOR) published by the Canadian Institutes of Health Research (CIHR) do exist and may benefit the process of patient engagement in this case, most notably through their Patient Engagement Framework. ¹⁹ Keeping its guiding principles in mind (inclusiveness, support, mutual respect and co-building) would assist the implementation team in their approach to engaging patients as knowledge users and push it further than passively engaging patients through methods such as mailed feedback.

Sustainability of KT interventions

While KT interventions have been increasingly used in Canada to implement research evidence into practice, the long-term sustainability of these interventions is not clear. To explore this topic, Tricco and colleagues conducted a scoping review to understand the literature on sustainability of KT interventions. Through their review, they found that few studies have focused on sustainability and that few studies even tested their KT interventions beyond 2 years. The authors recommend that planning for sustainability be done for KT interventions during the early development stages. Further, theories, process models and frameworks should be considered when developing and implementing sustainable KT interventions, as no published studies have done this. This case is clearly no exception to these issues around sustainability. When initially developing the plans for implementation of the SDM program, the team at CHEO should have considered how best to sustain the SDM program and ensure that it can endure changes in membership of the implementation team. Additionally, while the team utilized the KTA framework, this could have been improved to account for sustainability to ground the long-term success of the program with a theoretical background.

The utilization of frameworks and theoretical backgrounds is reinforced by Spassiani, Parker Harris and Hammel, as their study showed how the Promoting Action on Research Implementation in Health Services (PARiHS) framework could be used to aid implementation and sustainability. Through the use of such frameworks, researchers are able to better tailor their work to the realistic needs and environment in which they are conducting their research. Other frameworks, such as the global-context-sensitive conceptual framework proposed by Lapaige, exist in the literature to help develop effective and sustainable collaborations between knowledge users and producers. This reiterates that there is a wide

availability of guiding theories or frameworks that consider sustainability in KT initiatives, and utilization of these in this case would have likely increased the chance of long-term success for the SDM program.

Going back to the work of Spassiani and colleagues, they also state that a potential reason for a lack of long-term sustainability is that when implementation or research ends, so too does the resources needed to execute the program.²¹ For the implementation team at CHEO, this could mean that they need to provide continuous support for healthcare providers expected to use SDM with their patients, as information and training may fade over time.

Lastly, there are lessons to be learned from the work of Basaza and colleagues, as they provide interesting evidence about policies to sustain KT initiatives in the Ugandan healthcare system. They note that the main challenges for sustaining their KT initiatives are the lack of advocacy, lack of a framework for KT and a lack of funding and other resources. With these challenges in mind, they present a few policy options to address the lack of sustainability. The most relevant policy in this literature that may help CHEO to better sustain the SDM program is *capacity building for researchers and research users*. This policy would state that the healthcare sector should conduct training for researchers and decision-makers in KT, while also carrying out orientations in utilizing research and KT for all individuals both delivering healthcare and designing the healthcare system (focusing in specifically on politicians and decision-makers). This means that while the case at CHEO was a pilot program, the sustainability of the program is likely a reflection of the larger healthcare system. The implementation team could advocate for capacity building across hospitals and in the Canadian healthcare system to have a better infrastructure to support initiatives such as the SDM program.

CONCLUSION

The broader KT issues highlighted in this case note each play an important role in the ability of the SDM program to achieve its goal of helping children and their families to properly engage with the health decision-making process. It is imperative that they are actively engaged in all aspects of the IKT initiative. As key knowledge users in this setting, the themes in this case note have suggested ways to improve the implementation of the SDM program at CHEO.

When looking at the literature exploring *barriers and facilitators of IKT*, a key strategy revealed to improve the IKT approach was to provide practical training to healthcare providers and determine the true level of engagement from decision-makers. *Reframing 'expertise'* as a KT theme emphasized the need for the CHEO team to collect in-person feedback and ensure patients are actively engaged. There remains a need for a standard framework to facilitate patient input, but tools in Canada such as the SPOR may be helpful as this literature continues to grow. Lastly, the literature on *sustainability of KT interventions* reinforced the need for a guiding framework that considers sustainability early in program development to ensure long-term success. Additionally, the provision of continuous support for healthcare providers expected to engage with the SDM program and advocacy in the larger healthcare context to build capacity for these types of programs are expected to influence sustainability of the SDM program at CHEO. With these KT suggestions in mind, the implementation and long-term success of the SDM program may be improved to help better promote patient and family decision-making involvement at CHEO.

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Critically appraising translation of spinal cord physical activity guidelines in a community-based organization using integrated knowledge translation

A case note on:

Gainforth HL, Athanasopoulos P, Casemore S, Latimer-Cheung AE, Martin Ginis KA. Using IKT to translate the Spinal Cord Injury Physical Activity Guidelines in a community-based organization. In: McCutcheon C, Kothari A, Graham ID, editors. *How We Work Together: The Integrated Knowledge Translation Research Network Casebook. Volume 1.* Ottawa: Integrated Knowledge Translation Research Network. 2019; p. 45-50. Available https://example.com/here/be-nc/market-ph/9/

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SUMMARY OF CASE

SCI (Spinal Cord Injury) Action Canada, a network of researchers and community members, in collaboration with SCI Ontario and community-based organizations, aimed to develop and implement physical activity guidelines in the Ontario SCI population. The guidelines were developed using the AGREE II framework, which outlined the amount, intensity and type of physical activity required to obtain fitness benefits. SCI Action Canada used an integrated knowledge translation (IKT) approach to carry out end-of-grant knowledge translation (KT) by partnering with SCI Ontario, a community-based organization, to disseminate physical activity guidelines and evidence-based strategies to three target audiences: 1) people with SCI; 2) caregivers of people with SCI; and 3) SCI Ontario staff and volunteers. A partnered IKT approach was used throughout the development, implementation and evaluation of end-of-grant KT activities (dissemination) of guidelines and interventions.

Two key administrative staff members from SCI Ontario and Mr. Peter Athanasopoulos and Ms. Sheila Casemore were assigned to the project. SCI Action Canada assigned five researchers to work on the project: 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). SCI Ontario outlined their research and organizational priorities and the team worked in partnership to develop the evaluation tools. Analyses were conducted by the researchers with consultation throughout with community-based organization partners.

Between 2010 and 2013, the team launched three IKT projects to disseminate physical activity guidelines to the SCI population in Ontario. The projects were guided by the Diffusion of Innovation theory, the RE-AIM framework, the Knowledge-to-Action framework and the Theory of Planned Behaviour. Five manuscripts, 17 reports and three magazines articles were published from this project. The team accomplished four of the RE-AIM factors collectively in the three projects. The project reached and

disseminated guidelines to over 100 people with SCI, 140 caregivers and over 80 SCI Ontario staff and volunteers.

KNOWLEDGE TRANSLATION THEMES

During the implementation of physical activity guidelines for people with SCI in Ontario, the team working with SCI Ontario and SCI Action Canada used an IKT strategy; however, there were some implementation discrepancies, which I am going to talk about in light of the literature.

The first KT theme I am going to address is a **knowledge broker**. A knowledge broker is a mediator that plays an important role in managing the "know-do" gap by developing alliances and networks with, among and between policy-makers, stakeholders, producers and the users of the knowledge¹ by implementing evidence-informed strategies in a KT project.² In implementing physical activity guidelines in the SCI population, even though the team used evidence- and theory-informed strategies, a knowledge broker was not part of the team, which could have helped bring better implementation and maintenance or sustainability to the project.

The second theme that I will discuss is the **sustainability** of implemented knowledge. Sustainability is recognized as one of the most important issues of our time, and failure to tackle it poses a global challenge to the health-care system.³ KT interventions promote the uptake of research into practice and/or policy-making and can be referred to as research utilization, which in many KT projects has shown to be successful. However, the sustainability of the implemented intervention, which can be defined as the extent to which the KT intervention continues after the successful implementation, is not very well known. In this project four of the five RE-AIM factors were achieved, leaving behind 'maintenance,' which is a key step towards the sustainability of the implemented guidelines.

Lastly, I will elucidate on the involvement of **end-users in IKT** and how end-user involvement can bear better results in the implementation as well as sustainability. Integrated knowledge translation is a process of co-action between knowledge producers and knowledge users.⁴ The implementation of physical activity guidelines in the SCI community was carried out by an IKT approach between SCI Action Canada, SCI Ontario and community-based organizations but the end-users, which were the people with SCI, were not invited to be a part of the implementation project. Effective IKT can be achieved by early engagement of the end-users in the research process, not just at the dissemination stage.⁵

LEARNING GOALS

In this case note I will shed some light on the importance, activities and responsibilities of a knowledge broker and how the use of a knowledge broker can affect the implementation of knowledge. Secondly, I will highlight how paramount sustainability is to implementation science, as implementation is only effective if it is sustainable. Failure to sustain KT interventions affects patients and health systems, lowering the confidence in future KT activities. Lastly, I will talk about IKT and its benefits. Also, I will highlight the importance of engaging the end-users of the knowledge, in this case the SCI population, in an IKT project.

ANALYSIS

Knowledge brokers

A knowledge broker is a person or an organization who translates theoretical knowledge into practice by linking researchers and their target audience. An example of an organization acting as a knowledge broker is the World Health Organization (WHO), which is acting as a knowledge broker in European countries to help evidence-informed policy-making, which is demanded be taken to a global level after its success.⁷ Ensuring timely use of research evidence in health-care settings poses a constant challenge for health-care providers and policy-makers. Failure to enhance the use of knowledge results in poor quality health care. According to a systematic review of literature, a knowledge broker identifies, engages and connects with stakeholders, facilitates collaboration, creates tailored knowledge products, supports communication, facilitates and evaluates change, and supports sustainability.² A knowledge broker helps with the sustainability of the KT intervention, which is crucial because the sustainability is what makes a KT project successful in the longer run.² A study was carried out in which post-stroke patients were encouraged to participate in physical activity by health professionals working as knowledge brokers, mainly nurses and physical therapists. 10 The evaluation through pre- and post-questionnaire was done after the implementation, and the results concluded that use of a knowledge broker was effective in the post-stroke population. Similarly, the population with SCI can benefit from the use of a trained knowledge broker for better adherence to physical activity guidelines. ¹⁰ In this specific IKT project, the use of a knowledge broker could have generated better results in terms of end-users' involvement and designing a system that could have had better sustainability. The use of a knowledge broker is seen to improve the sustainability of a project and improve communication between parties in the KT process that involves end-users. During this IKT implementation of the physical activity guidelines, a PhD student from SCI Action Canada was working with the community-based organizations on a regular basis but she was not assigned the duties of a knowledge broker.

Regional networks can be a good choice when it comes to standardized knowledge brokers and highlight the need for a brokering strategy in the coming years to tackle the hurdles to incorporate research and policy to promote more research-informed policies. In implementation of the physical activity guidelines, SCI Action Canada, in collaboration with SCI Ontario and community-based organizations, played some part of knowledge brokering but a designated knowledge broker was not used. The use of a knowledge broker, concluding from the above literature, helps evidence-informed implementation with better sustainability of the guidelines.

To sum up, the use of a knowledge broker in a KT project facilitates systematic, sustainable and better implementation results, as a knowledge broker helps reduce the know-do gap by improving communications between knowledge producers and knowledge users in an evidence-informed manner, yielding better knowledge transfer.

Sustainability

In order to increase the uptake of knowledge through knowledge translation, the KT experts are fixated on overcoming initial implementation barriers. However, less work has been done to evaluate the viability of KT interventions in the long term, which is described as the degree to which a KT intervention lasts after its successful implementation. It can be defined as an intervention being in place for more than one

year after its implementation, or completion of the study or project funding cycle.¹⁴ As it is important to gain an understanding of how strategies are applied over time and to track their efficacy in 'real world' settings, different approaches for evaluating the sustainability of KT initiatives need to be determined.

The inability to maintain clinical interventions effectively once implemented is a major global problem with a loss of >\$200 billion per year spent on research. Massive research has been done on exercise interventions among persons with disabilities across a 10-year period (2006–2016). However, a secondary review revealed that most of the studies primarily focused on the outcomes right after the implementation of the guidelines and lacked a follow-up evaluation of sustainability, which highly demands the use of evaluation tools of the long-term effects and sustainability of the implemented knowledge. Focusing on sustainable post-intervention effects is important, because persons with disabilities need long-term measures to avoid physical inactivity and prevent deconditioning, which can greatly affect the health of a person with a disability. ¹⁷

In the implementation of physical activity guidelines in the SCI population by SCI Canada and SCI Ontario, the maintenance factor of the RE-AIM framework was not achieved, which means there was no strategy to make the implementation more sustainable. The team strived hard to implement the physical activity guidelines but failed to maintain or sustain them. Also, the project reached and disseminated guidelines to over 100 people with SCI, 140 caregivers and over 80 SCI Ontario staff and volunteers. The approximated prevalence of SCI in Canada for 2010 is 85,556 people, or 2,525 per million in Canada. According to these statistics the dissemination of the physical activity guidelines implementation project by SCI Action Canada and SCI Ontario was not widespread.

Through this discussion we can conclude that the sustainability of an implementation project is of the utmost importance as it justifies the billions of dollars spent on research. If it is not going to be sustained for long, the knowledge that has been made and implemented with financial, mental and physical expenditure goes in vain, especially the physical activity guidelines in a sedentary population where adherence to the physical activity is hard to achieve.

Integrated knowledge translation

Integrated knowledge translation needs partnership between researchers and the ultimate users of knowledge throughout knowledge production and implementation and is being extensively used as an essential strategy to address the problem of not using the produced knowledge. Collaboration between researchers and research users, or IKT, highlights the importance and integration of evidence in policy and practice. Knowledge users have specific research-related skills including context awareness and implementation potential. Researchers bring skills in both methods and content to collaboration. The sharing of power between researchers and knowledge users is the most important and useful in this approach, referred to as co-production of knowledge. This new way of working suggests that the shared synergies can contribute to better science, actionable research findings, evidence-informed policy-making and knowledge transfer among researchers, research users, policy-makers and stakeholders.

Integrated knowledge translation is defined as the collaboration between the researchers and research users, where the involvement of the ultimate users of the research is of the utmost importance for the

better uptake and sustainable implementation of knowledge. Researchers and knowledge users are equally responsible for the translation of knowledge into action and it is important to consult with and incorporate knowledge users throughout the research implementation process. Physical activity guidelines are only useful if the SCI population practices them. Improving the participation of the people with SCI in physical activity has many challenges such as negative attitudes, transportation, accessibility to places and equipment, and a shortage of programing Theory-based behavioural interventions are encouraging in changing the perception of the people with SCI, 2 but they do not bring about the desired behavioural change. In order to improve participation, a co-developed intervention was introduced in which the people with SCI were involved during the making and implementation process of the physical activity guidelines. Through this end-user involvement in the co-developed IKT intervention, the largest self-reported physical activity change was reported to date, which strongly advocates for the need of end-user involvement in the IKT process. 24

During the implementation of physical activity guidelines, SCI Action Canada and SCI Ontario do not mention the involvement of people with SCI, who in this case were the ultimate users of the guidelines, as from the research the very basic design of IKT is to incorporate the end-users for better implementation and sustainability of the knowledge. With the involvement of people with SCI, better implementation could be achieved in the case of physical activities that are subject to non-adherence problems. Using the IKT framework may result in more organizations being willing to initiate and develop IKT, likely eventually leading to more and higher quality collaborations for innovation in the health-care system. ¹⁹ The review of the literature supports IKT to be a helpful strategy in knowledge production and implementation that can transform our health system to become more efficient, evidence-based and better.

CONCLUSION

To sum up, the use of a knowledge broker in a KT project facilitates systematic, sustainable and better implementation results, as a knowledge broker helps reduce the know-do gap by improving communications between knowledge producers and knowledge users in an evidence-informed manner, yielding better knowledge translation. Hence the use of a knowledge broker could achieve better results in the implementation of physical activity guidelines in people with SCI.

The inability to maintain clinical interventions effectively once implemented is a major global problem with research waste measured at > \$200 billion per year. We need answers to the crucial issue of how to maintain successful implementation to maximize research impact and improve our health system. Sustainability is recognized as one of the most important issues of our time, and failure to tackle it poses a global challenge to the health-care system. Special focus must be put on the maintenance and longevity of implemented interventions.

Integrated knowledge translation is defined as the collaboration between the researchers and research users, where the involvement of the ultimate users of the research is of the utmost importance for the better uptake and sustainable implementation of knowledge. End-user involvement in this case could have resulted in better implementation and sustainability of the physical activity guidelines in the SCI population.

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Using IKT to translate the Spinal Cord Injury Guidelines in a community-based organization case note

A case note on:

Gainforth HL, Athanasopoulos P, Casemore S, Latimer-Cheung AE, Martin Ginis KA. Using IKT to translate the Spinal Cord Injury Physical Activity Guidelines in a community-based organization. In: McCutcheon C, Kothari A, Graham ID, editors. *How We Work Together: The Integrated Knowledge Translation Research Network Casebook. Volume 1.* Ottawa: Integrated Knowledge Translation Research Network. 2019; p. 45-50. Available https://example.com/here/be-nc/market-ph/9/

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SUMMARY OF CASE

Individuals with a spinal cord injuries (SCI) are often living inactive lives.¹ Researchers have suggested that there is a demand for health promotion initiatives aiming to promote physical activity within the SCI population.¹ In a study published by Gainforth and colleagues in 2011, SCI Action Canada, an organization composed of researchers and community members, developed physical activity guidelines specifying the exact amount, intensity, and types of exercises needed to achieve health benefits for those with spinal cord injuries.¹

SCI Action Canada received a grant from the Social Sciences and Humanities Research Council (SSHRC) Community-University Research Alliance, which allowed the organization to carry out many end-of-grant knowledge translation (KT) interventions. SCI Action Canada made the choice to partner with SCI Ontario to disseminate these guidelines targeting clients with SCI, support workers of SCI patients, staff and volunteers. Throughout the entire collaboration process between SCI Action Canada and SCI Ontario, an integrated knowledge translation (IKT) approach was applied.¹

There were three KT projects developed by two key administrative staff representing SCI Ontario in partnership with five researchers and a PhD student representing SCI Action Canada. On a weekly basis, the PhD student was working as a liaison between the researchers and the community partners. As a result of this study, five manuscripts, seventeen reports and three magazine articles were published. SCI Ontario adopted these guidelines and eventually implemented them into their organization. An implication of these guidelines was the inability to meet all criteria of the RE-AIM framework, which is a tool used by this case study to measure impact. 1,2

KNOWLEDGE TRANSLATION THEMES

When reflecting on the proposed IKT case study, three pressing knowledge translation issues became evident. It appears that the PhD student was attempting to work as a **knowledge broker** (KB) by acting as a mediator between the researchers and community members. In addition, the role of being a knowledge broker involves several diverse responsibilities, many of which were not carried out. Proper completion of KB duties would have significantly improved the study.

The inadequate consideration for the study's **sustainability** is the second major issue revealed throughout this IKT case study. In guiding this study, researchers used the RE-AIM framework (reach, effectiveness, adaptation, implementation, and maintenance) to identify the impact of this intervention.² Upon completion of the study, the element of maintenance and/or sustainability was unfortunately not achieved. The reasons for which sustainability was not achieved appear to be obvious and will be touched on briefly.

The minimal and indirect **involvement of patients and/or end-users** throughout this study will also be analyzed. When using an IKT approach, patient engagement should occur in order to achieve optimal benefits from a study's intervention and increase the likelihood of improving healthcare. Therefore, incorporating the end-user beyond what the researchers in this study have done may have allowed these KT interventions to positively create change within the SCI community.

LEARNING GOALS

The learning goals for the reader are to:

- 1. Develop a general understanding as to what exactly the role of a knowledge broker is and how to utilize this individual to provide maximum results;
- 2. Understand the importance of sustainability, especially in cases where funds are limited and longevity is crucial for stakeholder investment; and
- 3. Recognize the importance of effectively integrating end-users and/or patients throughout the research process.

ANALYSIS

Knowledge broker

In the case study by Gainforth and colleagues, SCI Action Canada assigned five researchers to collaborate with SCI Ontario. One of these researchers was a PhD student who was chosen to work with the community partners. Her role was to speak with partners multiple times per week and report progress to her supervisor weekly. This role in which the PhD student fulfilled is similar to that of a knowledge broker (KB). The PhD student, while acting as a KB, was not actually recognized as a KB.

The role of a knowledge broker (KB) has evolved throughout the last couple of decades, although today KB's are generally described as those who support and facilitate the collaboration between key stakeholders, engage in planning of activities, act as capacity builders, and evaluators. A knowledge broker has the ability to impact an IKT project greatly as their scope is extremely large and their expertise is diverse. When conducting research on the specific role of a knowledge broker, it became evident

this PhD student could have better utilized this opportunity with the community to further the success of this case study.

As discussed in numerous articles, it is crucial to understand the context of the KT project as this could lead to variation in the role of a knowledge broker. Even though the above appear to be common KB roles regardless of context, it is important to note that these can vary and this does not justify the lack of KB competencies and narrowed scope demonstrated in the case study by Gainforth and colleagues. It appears that the PhD student was solely functioning as a messenger between the researchers and the community partners. The case study did not mention any KT activities being planned, facilitated, analyzed, evaluated, or being carried out by the knowledge broker to benefit the IKT intervention.

The 'Role domains of the Role Model for Knowledge Brokering in health care' framework was published in 2016 by Glegg and Hoens, which categorizes the common activities of a KB.³ The following are listed as the five roles of a KB: information manager, facilitator, capacity builder, linking agent, and an evaluator.³ This framework neatly organizes concepts in which Conklin and colleagues as well as Dobbins and colleagues briefly state as central themes within their literature.^{4,5}

Gainforth and colleagues chose to adopt a Knowledge-to-Action (KTA) framework in order to guide their intended IKT project outcomes. The KTA model is utilized as a process model, useful in creating knowledge to improve applicability within healthcare. The Role Domains Framework by Glegg and Hoens was able to be seamlessly embedded into the commonly used KTA process model. Therefore, if the SCI physical activity guidelines IKT project chose to adopt the Glegg and Hoens KB Role domains of the Role Model for Knowledge Brokering and apply it within the KTA framework, the outcomes could have been extraordinary.

Applying the role domains of the *Role Model for Knowledge Brokering* by Glegg and Hoens within the KTA process can be difficult to comprehend, which is why I will critique the role of the PhD student and offer feedback to improve the case study. Within the KTA process, there is a step in which those involved are to assess barriers.² The incorporation of a KB at this stage could have been extremely beneficial to the study. A knowledge broker builds strong therapeutic and working relationships with community partners as well as key stakeholders.³ Knowledge Brokers often spend extensive periods of time, in this case multiple times a week, communicating with both parties.³ This appears to be an optimal opportunity for the PhD student to do a thorough assessment of the context, barriers, and needs present within this context. Not only would these conversations likely increase the success of an IKT intervention, it would likely foster trust within these relationships.

Further along the KTA process, a stage within the action cycle requires those involved to Evaluate Outcomes.² At this stage, those involved determine if the desired outcomes have been achieved.² If the KB was incorporated throughout the different stages of the KTA process, they would have known exactly what the desired outcomes from each party would have been. They would have also had the opportunity to evaluate what was successful and what could have been improved throughout the research process based on the achieved outcomes. In addition, due to in-depth conversations regarding the KT intervention, the KB would have the ability to recognize if outcomes were met.³ These examples support the need for a

KB's involvement within the entire KTA process and in turn, could have led to improved results within this case study.

Sustainability

The second issue that arose was the lack of sustainability of this project. Gainforth and colleagues utilized the RE-AIM framework to inform the project, although as mentioned in the conclusion of this case study, the team was unable to reach the fifth objective of the RE-AIM framework, which was maintenance. This project was not able to be maintained because sustainability was not appropriately considered.

There is no singular universal definition but sustainability is often referred to as the long-term effect and continuation of an intervention.^{6,7,8} Research shows that the majority of studies focus on the immediate adoption and implementation of IKT interventions and do not consider the sustainability of the project beyond the funding period.^{6,9} Stakeholders often want to know if the particular intervention is going to have a long-term impact on health prior to allocating funds, as their resources are often very limited.⁶

There appear to be several different elements which ultimately contribute to the sustainability of an IKT intervention. Scheirer and colleagues developed a framework in which sustainability is approached differently depending on the nature of the IKT intervention. According to this framework, there are six different categories of IKT interventions including: interventions requiring coordination among multiple staff; interventions implemented by individual providers; new policies, procedures and technologies; capacity building or infrastructure building; collaborative coalitions; and broad-scale system change. Depending on the type of intervention, different factors will influence the likelihood of sustainability. In this particular case, the Spinal Cord Injury Physical Activity Guidelines in a community-based organization IKT intervention by Gainforth and colleagues falls under the category of an intervention requiring coordination among multiple staff. The interventions mentioned in the proposed study require the involvement of SCI clients, support people/caregivers, staff, members from SCI Action Canada and SCI Ontario. Scheirer and colleagues addressed several different factors associated with this intervention related to finances, champions, resources, early planning, and support of administration staff, which would likely influence the sustainability in this case study.

The Cochrane Update *Predicting sustainability of intervention effects in public health evidence: Identifying key elements to provide guidance* conducted by Whalen and colleagues, accurately represented the framework by Scheirer and colleagues but also took into consideration several other studies published around the concept of sustainability within community-based interventions.^{6,7} Whalen and colleagues solidified ten key elements which may be able to address the issues around lack of sustainability.⁶ The ten elements of sustainability include: planning, evidence, commitment and support, engagement, champions, capacity building, evaluation, policy, and evolution/adaptation.⁶ The case study by Gainforth and colleagues did execute a few of these key elements such as engaging with important partners like SCI Ontario and building capacity such as training nurses; on the other hand, there were important elements lacking such as program champions and funding opportunities.¹

Champions are often known as "individuals who dedicate themselves to supporting, marketing, and 'driving through' an innovation." Many researchers consider the success of IKT interventions to be

based on the roles of opinion leaders, champions, knowledge brokers, and linking agents.¹¹ A champion in this context would maintain an ongoing relationship with SCI Ontario, raise awareness to organizational leaders within SCI Ontario, facilitate the training and the development of the SCI physical activity guidelines, and reinforce implementation of these guidelines.^{12,13} The appropriate incorporation of champions can be an effective strategy to achieve success regarding the physical activity guidelines in those with a spinal cord injury.

According to Whalen and colleagues, funding can be an important factor in determining the sustainability of IKT interventions. When assessing the funding in this particular case study, it appears that the only funding received was from a SSHRC Community-University Research Alliance grant. Even though this funding was a secure source of resources, some believe funding sources should be more diverse, meaning endorsement from numerous sources. In order to strengthen the study's funding resources, it would have been valuable if funding went beyond one grant agency extending to the local municipality, foundations, businesses, private contributors, or the public. The second consideration related to funding pertains to the availability of funds beyond the implementation phase. This case study did not mention the stipulations of the funding; it may have been beneficial if there were financial resources available until effects were maintained. As Whalen and colleagues determined, diversity and prolonged funding are factors to consider when planning for sustainability of an IKT study.

End-user involvement

When researchers and knowledge users come together and work collaboratively, the process can be referred to as end-user involvement. In this case, the end-user of this knowledge consists of individuals living with SCI, their caregivers, and SCI Ontario staff and volunteers. Typically, the researcher will collaborate with the end-user and discuss research priorities, research questions, interpret findings, and converse about the study's findings. End-user involvement in the integrated knowledge translation process is said to enhance accountability, transparency, trust, and accountability if done correctly and meaningfully.

Focusing in on the patient, the Canadian Institutes of Health Research developed a Strategy for Patient-Oriented Research (SPOR). The purpose of SPOR is to engage patients in all aspects of research to improve the healthcare system within this country. SPOR's National Steering Committee developed a Patient Engagement (PE) Framework to explain concepts, principles, and areas where patient engagement can be adopted. He desired outcomes of PE are creating inclusive mechanisms and processes; establishing respectful collaboration amongst patients, researchers and health care providers; valuing the experiential knowledge of patients as part of the research process; informing and co-directing research by patients; and lastly, the common goal of timely implementation of quality research. This framework published by SPOR has four guiding principles: inclusiveness, support, mutual respect, and co-building. The PE framework is an academic piece in which SPOR is extremely proud and is continuously reevaluated as SPOR is implemented.

When reflecting on the patient involvement within the Gainforth and colleagues case study, SCI Ontario assigned two key administrative staff members working within client services to be representatives.¹ Although SCI Ontario staff is an end-user of the knowledge being produced as well as working directly

with SCI clients, it does not replace the incorporation of patients directly. Patients are the true end-users of the SCI physical activity guidelines and should carry equal involvement throughout the IKT process.¹⁷

The PE framework is a great tool to ensure that patients are effectively collaborating with the researchers to hopefully improve health outcomes and better the healthcare system.¹⁷ Gainforth and colleagues should have begun their study with the recruitment of patients directly, in addition to the SCI Ontario administrative staff. Patients are experts in their spinal cord injury and their lived experiences are unique and can offer highly valuable information to the study.¹⁷

The patient should have begun their contributions in the IKT process by collaboratively determining the research question and research objectives.¹⁷ After reading the case study and working within the spinal cord injury unit as a Registered Nurse, it is evident that physical activity is an important component of holistic health given their limited mobility. What remains unclear is whether the patients (end-users) consider this to be a priority. Therefore, given that the research question was determined by others, without patient involvement, the objectives of the research were clearly researcher driven.

The evaluation of the research project did not specify any incorporation of the patients, although the PE Framework believes in a crucial phase of involvement. There was a brief section of the case designated for the discussion around impact and implications. Within this section, Gainforth and colleagues mention that five manuscripts, seventeen reports and three magazine articles were published. There was no mention of researchers reporting back or verifying the results with patients. As the PE Framework suggests, there was no verification if the outcomes were of value to the patients or were supported by these individuals themselves. The lack of patient involvement in this case study was a disappointment and being a healthcare professional in this specific and unique field, I do feel patients would have benefited from research tailored to their specific needs.

CONCLUSION

The purpose of this paper was to identify knowledge translation issues needing improvement to increase the success of this case. The first issue was related to the lack of a legitimate knowledge broker. This paper discussed ways in which a knowledge broker could have been incorporated in this study specifically to achieve maximum results. The second issue identified in this paper was the lack of consideration for sustainability. An introduction to the ten elements of sustainability by Whalen and colleagues were discussed in hopes of providing solid feedback to create long term achievements. The last issue was regarding the lack of patient involvement throughout the IKT process. The PE Framework model published by SPOR was introduced to provide Gainforth and colleagues and other researchers with some ideas as to how to effectively engage end-users. ¹⁷ In conclusion, effective execution of these guidelines using the feedback provided within this paper can benefit the spinal cord injury population greatly.

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

A case note on:

Kastner M, Hayden L, Makarski J, Lai Y, Gerber N, Jhajj, Chan J, Treister V, Straus S. 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. In: McCutcheon C, Kothari A, Graham ID, editors. *How We Work Together: The Integrated Knowledge Translation Research Network Casebook. Volume 1*. Ottawa: Integrated Knowledge Translation Research Network. 2019; p. 51-56. Available here.

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SUMMARY OF CASE

The case that will be explored in extensive detail is called the "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."^{1,2} Currently, there is a lack of comprehensive guidance for rigorously developing knowledge translation (KT) tools and products for older adults (65+) who suffer from highburden chronic conditions^{1,2}. The goal of this specific case was to develop a patient-centered, evidencebased, user-informed, web-based KT tool called "KeepWell" with the potential to optimize selfmanagement practices of older adults and to help facilitate the clinical decision-making of health professionals in the context of multimorbidity^{1,2}. To address this goal, the knowledge-activated tools (KaT) framework was designed and developed by KT experts by conducting a systematic review to ensure the best available evidence was used to inform multimorbidity strategies and interventions^{1,2,3}. The overall purpose of this framework is to help "a wide range of knowledge users (researchers, providers, policy makers) develop, disseminate, implement, sustain or scale up optimized KT tools and products^{1,2}" (p.51). After development of this KaT framework, it was applied and used to help create the KeepWell tool after numerous revisions, iterations and optimizations were incorporated based on the input from the iKT team were implemented^{1,2}. Overall, the KeepWell tool can have a positive impact and influence on chronic disease management because it was co-created by older adults (end-users), it responds to most identified challenges faced by older adults, the features on the tool are innovative and engaging, and it has great potential for large scale and spread^{1,2}.

KNOWLEDGE TRANSLATION THEMES

Theme 1: Co-design of interventions and/or tools

The scope of this theme is to identify how patients can be actively involved in the co-design of interventions and/or tools because current research suggests that successful implementation happens when

the patient is involved and integrated into every step of the research process⁴. In regard to the case specifically, numerous iKT activities were used; however, one in particular was having the KeepWell tool co-designed by numerous stakeholders^{1,2}. This was achieved by allowing patients who were members of the iKT team to participate in providing insight regarding the development of "objectives, research questions, study methods, project plans and timelines" via email, in person meetings, and through teleconferences^{1,2} (p. 53). Further, there were "nine focus groups [that] were held with our patient co-design team throughout the tool development, from the exploration stage to the final beta version^{1,2}" (p.54). Based on these interviews, feedback was collected through group discussions, observing the tool prototype, and feedback surveys to help guide further iterations, revisions and optimization strategies for the tool^{1,2}.

Theme 2: How to design and disseminate knowledge products

The scope of this theme is to investigate how to design and disseminate knowledge products in different formats that are tailored and easily digestible for lay persons. Given the recent advancement in technology, there are various innovative strategies that can be utilized to support the dissemination of key KT information. For example, the emerging use of technology is evident in this specific case because the KeepWell tool is an innovative and creative web-based platform that can be accessed using a computer/laptop, mobile phone or tablet with the intention of providing older adults and clinicians guidance regarding multimorbidity self-management practices^{1,2}. This tool is beneficial and makes a positive impact because it is seen as a creative way to facilitate effective and efficient collaboration among end-users by making it engaging and tailored towards the target audience^{1,2}.

Theme 3: Web-based KT technology

The scope of this theme is develop a deeper understanding of what web-based KT technology is and how it can effectively be used as a strategy for increasing the uptake for disseminating health research. In regard to the case, the KeepWell tool is a web-based technology aid that integrates evidence-based information from the top 11 high-burden chronic conditions (e.g., heart failure, diabetes, dementia, stroke, arthritis, depression, etc.) that affects older adults, by providing customized lifestyle recommendations that are easily digestible^{1,2}. To ensure the KeepWell tool meets the demand for usability and satisfaction, it follows clinical practice guidelines by offering a clinical decision support component and allows information to be customizable^{1,2}.

LEARNING GOALS

After reading this case note, the reader should be able to:

- 1. Understand how to involve patients in the co-design of interventions and/or tools
- 2. Understand how to apply innovative KT alternatives or strategies to disseminate knowledge products to lay persons
- 3. Learn how to increase the uptake of technology-enabled KT

ANALYSIS

This next section will provide a critical analysis of current literature that is related to the three KT themes that were addressed in the section *Knowledge Translation Themes* briefly and make connections relating

it back to the case. The purpose of this analysis is to develop a deeper understanding of what is currently being done in the field by examining both gray and academic literature.

Co-design of interventions and/or tools

Over the last few years, the utilization of co-design methods have become more popular in health care. The use of co-design methods "involves the equal partnership of individuals who work within the system (healthcare staff), individuals who have lived experience of using the system (patient and their families/carers) and the 'designers' of the new system (whether that be IT personnel in terms of electronic platforms to improve efficiency or researchers in terms of designing interventions to improve health systems⁵" (p.2-3). There are numerous benefits to utilizing co-design methods as it involves⁵:

- The ability to collaborate with other stakeholders/ knowledge users to help develop and design a new product;
- It provides the opportunity to use each other's knowledge;
- Allows the opportunity to build meaningful and trustworthy relationships by using each other's knowledge, resources, and integrating everyone's contributions;
- It enables the possibility of achieving better health outcomes for individuals who are most likely to be impacted and benefited (indirectly or directly).

The big question is "how can patients be involved in the co-design of interventions and/or tools?" After extensive research of the literature, an example of how patients can be involved in the co-design of interventions and/or tools stems from the Canadian Institutes of Health Research (CIHR) as they recognized the urgency and importance for active patient engagement in the health research process by developing a strategy in Canada called the Patient-Oriented Research (SPOR) framework⁴. The purpose of the SPOR framework "is for patients, researchers, health care providers and decision-makers to actively collaborate to build a sustainable, accessible and equitable health care system and bring positive changes in the health of people living in Canada⁴". In regard to this framework, patients (referred to as "SPOR Partners") are considered a key stakeholder as they are a main focal point because they must be involved and integrated into the research process (start to finish, step by step) to ensure successful implementation⁴.

There are four guiding principles that underpin this SPOR framework that are imperative to ensure proper integration of patient engagement: inclusiveness, support, mutual respect, and co-build⁴.

- **Inclusiveness:** "patient engagement in research integrates a diversity of patient perspectives and research is reflective of their contribution i.e., patients are bringing their lives into this⁴".
- **Support:** "adequate support and reflexibility are provided to patient participants to ensure that they can contribute fully to discussions and decisions. This implies creating safe environments that promote honest interactions, cultural competence, training, and education. Support also implies financial compensation for their involvement⁴".
- **Mutual respect:** "researchers, practitioners and patients acknowledge and value each other's expertise and experiential knowledge⁴".

• **Co-build:** "patients, researchers and practitioners work together from the beginning to identify problems and gaps, set priorities for research and work together to produce and implement solutions⁴".

Based on the SPOR framework, current literature suggests that the level of patient engagement will help improve the relevance of research by allowing the integration into practice and policy, it will improve the delivery of more effective and efficient health services, and it will ultimately enhance the overall quality of life for patients⁴. Further, according to Nass, Levine and Yancy (2012), "engaging patients in health care research makes (investments in) research more accountable and transparent, provides new insights that could lead to groundbreaking discoveries, and ensures that research is relevant to patients concerns. The international experience with engaging citizens and patients in research has shown that involving them early on in the design of studies, ideally as early as at the planning stage, leads to better results⁶" (p.8).

This can be observed in a study conducted by Barbic et al. (2019), where the authors applied the SPOR strategy to gain insight regarding the self-management needs of young Canadians (aged 15-18 years) who struggle with mental health disorders⁷. In this specific study, the authors involved youth patients in the planning stage and ensured they were actively engaged throughout the entire research process⁷. The integration of having youth patient partners included in all phases of the study provides the opportunity for their voices to be heard by allowing them to express and share their lived experiences, and as a result it enhances the significance of the research findings⁷. To further elaborate, literature also suggests that integrating patient engagement in iKT can help address health disparities and improve the overall delivery and effectiveness of interventions⁸.

In relation to the case, the use of patient engagement seems sufficient as patients were actively involved in the co-design of the entire research process of the KeepWell tool^{1,2}. This is evident as the iKT team was comprised of 15 team members that were involved at every phase of the three-year research project which consisted of:

- Older adults with multimorbidity (these were the end-users of the KeepWell tool)^{1,2}
- Clinicians (these were mostly geriatricians and family physicians because they were who were most engaged and involved in the self-management of multimorbidity)^{1,2}
- Policy-makers (they are decision-makers that are interested in identifying solutions to address chronic disease management in the rapidly aging population)^{1,2}
- Researchers (they can provide their expertise and interest in advancing KT practice and science)^{1,2}
- As the research advanced, there were other knowledge users that were involved and carried on board for the co-design team that consisted of 10 older adults who suffer from multimorbidity^{1,2}. These individuals were recruited from the North York General Hospital and from St. Michael's Hospital.^{1,2}

Therefore, it is clear that this KeepWell tool did a great job when involving patients in the co-design of the tool by integrating them in every phase of the process and as a result this tool provides promise to improving the self-management of monitoring chronic conditions for older adults^{1,2}.

How to design and disseminate knowledge products

According to the Canadian Institutes of Health Research (2012), "knowledge translation activities should focus on non-academic modes of communication, and make extensive use of lay language and popular formats such as websites, podcasts, webinars, and YouTube videos, as well as film, theatre, and art^{9,10}". This can be considered an end-of-grant KT activity because the purpose is to disseminate this information to different knowledge-user audiences by enabling the increase and uptake of research to more broad audiences instead of only targeting the research community⁹. Therefore, it is imperative that whatever KT activity is chosen, it is evidence-based, thought to be most effective for the target audience (knowledge users), and is tailored to their specific needs⁹.

After extensive exploration of the literature, it is evident that there are numerous formats that can be used to disseminate key KT messages, which are referred to as creative knowledge translation¹⁰. For example, digital storytelling, infographics, social media, game, film, music, and animation are all considered creative formats that can be utilized; however, this is not an exhaustive list¹⁰. When choosing alternative formats to relay health information, it is critical to ensure the content is easily digestible for knowledge users and tailored appropriately for its intended applicability and usability^{9,10}.

There are many advantages to utilizing creative KT strategies because current literature suggests that it can aid comprehension, improve subject matter uptake and attitudes from end-users, and can provide the opportunity for new and innovative methods to emerge^{9,10}. Additionally, research by Eysenbach et al. (2015) suggests that using different creative KT methods can also improve recall and individual attitudes with low health literacy skills¹¹. Based on these findings, it suggests that creative techniques and approaches can be beneficial as a KT technique; however, in order to continue with traditional KT strategies, "evaluation and monitoring are key to verifying the effectiveness of engagement, comprehension, and recall of knowledge users regardless of the method of delivery^{10,11,12}" (p. 7). This is evident in the case because one of the iKT activities was to constantly monitor, evaluate and collect feedback from all team members to see what can be improved^{1,2}. By having this as an activity, it allowed for the constant revisions, iterations and optimizations of the tool to ensure it met the requirements for end-users^{1,2}. As a result, the KeepWell tool is seen as an innovative and creative way to facilitate effective and efficient collaboration among end-users because it has been proven to be engaging, interactive, and an easy to use product^{1,2}.

Web-based KT technology

Over the last numerous years, there has been an increasing interest in utilizing the internet as a platform for KT and the use of web-based KT resources as a strategy for disseminating health research. Web-based KT can be defined as "e-learning products that translate evidence-based knowledge to disseminate information that increases awareness, informs clinical practice, and stimulates practice change^{13,14}". Based on a systematic review conducted by Samoocha et al. (2010), there is evidence to support the effectiveness of utilizing the internet as a platform for interventions and/or tools because it increases patient empowerment, improves health outcomes, increases specified knowledge, achieves behavioural change, and it enhances participation in healthcare¹⁵.

Patient empowerment is defined as the enhanced ability for patients to actively understand and influence their own health status; whereas the World Health Organization (WHO) describes patient empowerment as a "prerequisite for health and a proactive partnership and patient self-care strategy to improve health outcomes and quality of life among the chronically ill¹⁵". Based on this review, it is evident that webbased interventions can show a positive impact on the level and overall engagement regarding patient empowerment because the patient is able to digest and comprehend the information provided to them when utilizing a web-based technology as a tool ^{15,16,17}.

In relation to the case, the KeepWell tool seems to effectively utilize and meet the requirements for web-based KT^{1,2}. This is evident in the case because the KeepWell tool was developed to be user-informed by having patients integrated into the co-design of the product to ensure it meets the user-requirements (i.e., meeting patient empowerment and enhances overall participation in healthcare)^{1,2}. Further, this tool aims to improve health outcomes by targeting older adults to be more informed about their chronic conditions, and as a result it increases specified knowledge uptake and ultimately achieves behavioural change^{1,2}.

CONCLUSION

After reviewing and conducting an analysis on three major themes that emerged from the case, it is evident that this web-based KT technology, the KeepWell tool, can have a positive impact on improving self-management practices of chronic conditions for older adults. In relation to the learning goals stated above:

- Learning goal reference 1: It is evident that the level of patient engagement is imperative in the codesign of interventions to ensure participants share their voices and opinions. An example of this is integrating the SPOR framework as part of an intervention as a strategy to help achieve sustainable and meaningful results.
- Learning goal reference 2: Utilizing innovative KT alternatives to disseminate knowledge products to lay persons is imperative; however, in order for the information to reach the intended audience, it must be tailored appropriately so it is easily digestible.
- Learning goal reference 3: Given recent advancements in technology, it is imperative to take advantage of understanding how to effectively and efficiently increase the uptake of technology-enabled KT interventions or tools.

Broader KT issues are important specifically for this population (older adults) because this is an at-risk and vulnerable population who suffer from managing multiple chronic conditions. It is therefore imperative to disseminate these findings effectively and efficiently to ensure they reach a larger audience, as they will help inform research and clinical practice by utilizing innovative and creative techniques or strategies.

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Scaling up IKT: larger problems or larger solutions?

A case note on:

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SUMMARY OF CASE

This case centres around understanding the inter-regional variation in patient-flow performance across several health systems in Western Canada. Patient flow ensures that patients get the care they need when and where they need it. However, most health systems currently struggle with stagnant flow; this is easily seen in Emergency Departments across the country. This is a system problem that requires significant changes to resolve the issues; however, there is a lack of evidence to guide a complete system transformation. This led leaders in the Regional Health Authority to ask Sara Kreindler to examine patient flow strategies in surrounding Health Authorities.

Kreindler started by forming research partnerships with all urban health regions in Western Canada. She found the key point people in each organization and prioritized their knowledge needs to encourage participation. This allowed her not only to develop relationships with organizations but also key managers, creating a two-level integrated knowledge translation strategy to build partnerships. This involved using existing multiregional bodies for research capacity and to manage some logistics. This also made it easier to meet with decision makers to help develop a discussion document with 11 key questions about the planned research.

This helped in their funding application and allowed for open dialogue for their research plan with their partners. Currently they are in the data analysis phase. This process showed that some parts of integrated knowledge translation scaled easily, like the skills used to build relationships. However, some were more challenging, such as finding common goals and relationship management. Finally, it proved challenging to build trust and shared responsibility since this was across many jurisdictions.

KNOWLEDGE TRANSLATION THEMES

Throughout this case, three key knowledge translation themes emerged: **evidence-based policymaking**, **micropolitics of decision making** and **trust between stakeholders**. Currently, there is a lack of robust evidence that can guide a transformation of the health care system. In this case, Kreindler built a

multijurisdictional research network to co-produce knowledge that can be used to inform policy. It also became clear in the case that finding common research goals was difficult, impacting the depth of research.

The challenge of the micropolitics of these decisions only grew as the network grew. At one point, Kreindler even thought of breaking up the network into smaller projects due to some of these challenges, specifically, finding common priorities and having a shared sense of responsibility over the research decisions. This made it difficult to build trust between stakeholders, which is a needed for integrated knowledge translation. Trust is especially important in this case as Kreindler worked to create a two-level integrated knowledge translation strategy involving organizations and middle managers to help co-produce knowledge.

LEARNING GOALS

Readers of this case note should be able to: (1) understand the different challenges faced when an integrated knowledge translation intervention grows in both geographic and partner size; (2) apply a framework to understand the factors that influence implementation of health care policies and practices; (3) analyze the needs and relationships between different stakeholders in integrated knowledge translation.

ANALYSIS

Evidence-based policy making

To understand the underlying context of this case, it is important to understand how funding decisions are made in the Canadian health care system. Through various formulas, money is allocated by provinces to cover the costs of health services delivered in various settings. This funding is to cover the basic costs of operating. There is separate money allocated for research and improvement; however this funding is more difficult to access. Even though health care makes up almost half of government spending, there are few research projects or innovations that last beyond their initial funding. Many ideas get to the pilot project stage but lack long term security, limiting the assessment that can be used to develop policy. The researchers or clinicians behind these projects often have competing interests that do not allow them to focus their attention toward these projects that are designed to help decision makers. This often means that decisions are made by policy makers who do not have access to timely and relevant research to craft policies that can improve the system.

This overabundance of pilot projects, rapid turnover and lack of reward can lead to fatigue and overlooking evidence. This has led to the increase in partnerships between researchers and decision makers or creation of hybrid roles, which can help make it easier for organizations to put evidence into policy and practice.⁴ This can help balance the need to innovate and organizational realties. This is something that Kreindler tried to leverage as they wanted to learn how other health authorities made decisions to develop their patient flow strategies. This project worked on a two-level approach as they quickly identified that they needed information from managers and organizational leaders. In order to gain access to the managers, the researchers had to prioritize the organization's knowledge needs as well as appreciate the interests of managers.

These groups ultimately will be the end users of this knowledge and to have an effective integrated knowledge translation strategy there must be an understanding of what users need. One way to look at this is by using the framework proposed by Chaudior *et al.* for predicting implementation outcomes.⁵ Causal factors highlight the different sources and the interplay of factors that will affect the implementation of an idea. With large scale projects there are many more perspectives at each level to consider, making it difficult to find common ground leading to nonspecific outcomes. This means that the research or evidence can lack the context and depth to inform systematic change. On the other hand, small projects often lack the generalizability to be used as evidence to change policies by other organizations, as the projects might only have worked under certain causal factors.

Even when research evidence is used to inform policy in one jurisdiction, there is often little uptake among other areas.² There is a lack of horizontal collaborative mechanisms to share lessons learned from pilot projects across jurisdictions.² Kreindler addresses this head on and worked to develop a multijurisdictional network allowing similar systems to work together to produce and share knowledge. However, at times in the case it has proven difficult to find common ground between researchers, organizations and health authorities.

Micropolitics of decision making

To coproduce knowledge, groups must work towards common goals and share responsibility for the project's objectives and outcomes. However, as more partners are brought in, the scope of the project becomes more general. As outlined before, for the project to generate evidence that can be used for policy it must have depth and be generalizable. In order to do this, Kreindler used their experiences working with decision makers to understand the needs of organization and try to incorporate it in the project. It is important to understand even when basing decisions on evidence, that decision makers and organizations will apply their own values and lens to the evidence. This is influenced by a number of factors including the organization's culture, goals, leadership and many other factors. This context can only be understood by engaging with them throughout the process, especially when establishing a research plan. This skill set scaled well from small scale projects and the project enjoyed active participation from many decision makers.

However, the challenge grows as you also try to work with different organizational needs and values.⁷ Even in this case, some organizations' needs fell below others, which proved to be challenging for Kreindler. This led to reduced engagement from some partners or reduced access, which led to slow downs. This plays out in small- and large-scale projects; however, the impact of these political disagreements could derail an entire project. Kreindler reflects that their status as a newer researcher added to the resistance they faced. However, they quickly learned to manage these challenges by staying engaged with decision makers and bringing it back to their shared priorities and values.⁷

This case also highlights the importance of both project and relationship management. There are many logistical challenges that arose as the project grew, including increased administrative demands. As a multijurisdictional project it required ethics approvals at many different parties, which took almost a year to acquire. Additionally, to limit the burden on their partners, the group tried to meet during other multijurisdictional conferences and use technology when possible. However, this meant limited face time

with peers, increasing the time needed to make decisions. These are just some examples of internal and external factors faced by Kreindler. They can cause delays that reduce the timeliness of their research and impact the relationships between researchers.

These external and internal factors have a strong influence on the political realities researchers must work within. The interplay of these factors is illustrated in the conceptual framework proposed by Lapaige. All of these factors must be considered when trying to understand how organizations make decisions. The influence of certain factors grows with the size of projects. For example, the national-level factors such as regulations can slow a project that needs multijurisdictional approval. Also, the increased number of partnerships requires more maintenance to ensure synergy as well as more individual-level factors.

In order to manage the relationships it is important to establish clear expectations and role clarity.⁴ To minimize the delay caused by social and political complexities, members need to have realistic expectations of how the project will operate. Researchers will also need to agree on how they will work together in order to avoid polarization or alienation of members of the group. This can only happen if there is a sense of trust between different organizations, decision makers and researchers.

Trust between stakeholders

Trust is vitally important to any integrated knowledge translation strategy. It is well known that regular interactions between researchers and policy makers increase the prospects for research use. These interactions in a shared setting allow them to form a trusting relationship. Decision-makers who actively engage in this process are much more likely to use evidence when making decisions. They are able to help coproduce the knowledge and add value to the insights provided. For example, researchers gain valuable insider knowledge about culture and organizational politics. This can help them better align their research with specific organizational concerns. They learn from each other by actively working together to reach common goals and shared successes.

In order to continue to build trust its important to focus on common goals and interests as the focal point for a critical discussion. ¹⁰ This was utilized by Kreindler when it felt that the project might need to be split into smaller projects. By working with the stakeholders, they concluded that they would be losing sight of their original goal by breaking up the project and decided to keep pushing ahead. This was likely a result of the trust that the group had built with Kreindler. This trust was built through small and large actions: small actions like minimizing additional travel for partners and administrative burdens, and large actions like collaborative decision making where possible and transparent discussions with stakeholders. This helped them see each other as equals.

CONCLUSION

As an integrated knowledge translation project increases in size it will be faced with increasingly complex challenges. This will strain the knowledge translation issues that have been discussed around evidence-based policymaking, micropolitics of decision making and trust between stakeholders. For the integrated knowledge translation project to be useful to individuals and organizations they will need to generate evidence that has depth and is generalizable. It must also account for the various needs and values of the groups involved, along with considering their internal and external pressures. Finally, researchers and

decision-makers must trust and see each other as equals. It is important throughout this process that researchers do not lose sight of their original goal while navigating these knowledge translation issues. This case shows that while it may be possible to scale up a project, they tend to resist alignment and sometimes "small is beautiful."

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Developing, implementing and evaluating an audit and feedback system in Ontario's maternal-newborn hospitals using an integrated knowledge translation approach

A case note on:

Dunn S, Reszel J, Weiss D, Graham ID, Sprague AE, Walker M, on behalf of the Maternal Newborn Dashboard team. The experience of using an integrated knowledge translation approach to develop, implement and evaluate an audit and feedback system in Ontario maternal-newborn hospitals. In: Kothari A, McCutcheon C, Boland L, Graham ID, editors. *How We Work Together: The Integrated Knowledge Translation Casebook. Volume 2.* Ottawa, ON: Integrated Knowledge Translation Research Network. 2020; p. 2-6. <u>Available here</u>.

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SUMMARY OF CASE

Evidence supports the use of audit and feedback systems to improve clinical outcomes by comparing clinical practice to evidence-based benchmarks. The highly variable clinical care in Ontario's maternal-newborn hospitals prompted the Better Outcomes Registry & Network (BORN) Ontario, an internet-based data collection system, to implement and evaluate the use of the Maternal Newborn Dashboard (MND), an electronic audit and feedback system that visually identifies evidence-practice gaps associated with six key performance indicators.

Target audiences included Ontario's health-care providers, decision-makers, and maternal-newborn care leaders. An integrated knowledge translation (IKT) approach was implemented via an inter-organizational partnership between the knowledge-producer organization (BORN) and the knowledge-user organizations (Ontario maternal-newborn hospitals),² to develop, implement and audit the effectiveness of the MND. An implementation plan was created from the collaboration of the development committee and BORN leaders. Implementation was supported by designing communication and education strategies. An IKT strategy was used to construct a research protocol to evaluate the dashboard's success. Iterative problem solving, deliberative dialogue and consensus building were instrumental elements of this IKT approach.

The IKT team faced challenges including achieving consensus within the interprofessional team, time commitment issues, engaging all stakeholders and making the IKT process transparent to end-users not involved in the IKT process.

KNOWLEDGE TRANSLATION THEMES

Importance of integrated knowledge translation

Researchers and BORN community members collaborated to conduct an IKT process. Clinicians embedded in the sites where the MND would be implemented were involved, allowing the research team to identify key barriers to uptake and address them prior to implementation. The interprofessional team faced challenges such as struggling to manage "actual/perceived power imbalances" and achieve consensus within the team.

End-of-grant knowledge translation

End-users not included in the interprofessional team felt confused about the development process of the MND, believing the MND to be developed without clinician involvement. However, essential stakeholders were involved throughout the project. These factors affected the clinical uptake of the MND. A properly developed end-of-grant knowledge translation plan could have assisted in alleviating some of these tensions, allowing end-users to have trust in the knowledge products produced from such projects.

Utilizing knowledge brokers effectively

The IKT team struggled to achieve consensus between stakeholders and engage all stakeholders post-project. These issues could have been mediated with the effective use of a knowledge broker, who can play a key role in the creation, utilization and dissemination of knowledge.

LEARNING GOALS

- (1) Learn the importance of IKT.
- (2) Gain an understanding of the importance of an end-of-grant knowledge translation plan.
- (3) Identify strategies to utilize a knowledge broker effectively within imbalanced social structures.

ANALYSIS

Importance of IKT

The know-do gap is a major societal issue facing the field of knowledge translation, traditionally conceptualized as a knowledge transfer issue - a failure to effectively disseminate research findings to knowledge users.³ However, recently organizations and researchers have begun to understand that the know-do gap is more correctly a knowledge production problem.² Users fail to utilize research findings as these findings do not address questions important to them.³ Integrated knowledge translation aims to increase the application of research by involving knowledge users as equal partners (experts) while valuing and recognizing non-clinical skills and non-research evidence.^{3,4} The engagement of knowledge users in the IKT process is a critical predictor of uptake of research findings.³

There are five key elements of IKT, also known as research co-production: active agents, equality of partners, reciprocity and mutuality, transformative nature and facilitation.⁵ Each stage of the IKT project functions as an opportunity for collaboration between knowledge producers and knowledge users.⁴ Knowledge users should be involved from identifying research questions relevant to them to the point of evaluating the implementation of research findings.^{2,4}

Health research should be driven by knowledge user needs rather than researcher needs, to ensure issues relevant to end-users are being addressed,^{4,5} allowing end-users to act as active agents. This involves the recognition of the fact that individuals and groups directly and indirectly affected by the implementation of research findings act as key change agents in the knowledge translation process.⁵ In the case study, the end-users can be seen as being treated as active agents and driving the establishment of the research process. BORN Ontario began development, auditing and implementation of the MND in response to the wide variation in maternal-newborn care in Ontario hospitals. Key stakeholders involved in the project included representatives from the diverse groups of their target audiences, as these were the groups which would be interacting with MND after its implementation.⁶

By incorporating more end-users into the IKT process, researchers are allowing them to play more active roles; however, there is a hope that these users play an equal role in the development and implementation of research.⁵ This requires recognizing that evidence can come from different sources.³ Another key element of achieving partner equality is to operate with a "small strategic core," which involves working with a small group of researchers and end-users representative of relevant stakeholders. This group must have strong working relations, possibly extending past the culmination of the project.⁵ Throughout the MND project, small working groups with wide stakeholder diversity were used to allow for effective communication and maintain efficiency, in addition to using previously established relationships, where possible. However, the interprofessional team still struggled to maintain partner equality due to end-users and researchers perceiving power imbalances within the group.⁶

IKT projects should be mutually beneficial to both knowledge producers and knowledge users. This requires knowledge users and researchers to be open to each other's ideas and experiences.⁵ In addition, knowledge users were involved in the development of research questions, interpretation of results and the implementation of findings.⁷ The development of the MND mutually benefitted the organizations involved. Through the development and use of the MND system, BORN Ontario aimed to increase awareness about performance and quality of care issues arising from the data input into their system, while Ontario maternal-newborn hospitals intended to improve these issues.¹ However, the project failed to have sustained collaboration throughout the IKT project. While 91% of relevant stakeholders were involved in the development stage of the project, this number dropped to 62% by the implementation stage.⁶ Ideally, stakeholder engagement should increase over the lifecycle of the project,⁷ as there needs to be increased end-user engagement to effectively understand and address the context of implementation sites. This could have had an impact on the clinical uptake of the MND.

Successful IKT projects have lasting effects by transforming the way health research is conducted.^{5,8} Collaborating with end-users increases productivity in addition to the capability and potential for future engagement.⁵ IKT processes involve the group identity transforming towards acceptance and appreciation of the unique assets IKT allows the team to harness and build.^{5,8} IKT projects aim to transform practice rather than merely translate acquired knowledge.⁹ This approach values discourse and conflicts as it allows the team to grow and challenge themselves. Boundaries breed from diversity. Change can only occur when new boundaries are crossed and new perspectives considered.⁹ Greenhalgh et al. suggest that such a process requires power relations to be clear and conflict to be task-oriented rather than interpersonal.¹⁰ The team in the case study faced some conflict and inability to come to a true consensus,

possibly as some conflict was interpersonal rather than directly task-oriented. However, the team also valued the unique assets each member brought to the team.

The final element of research co-production is facilitation.⁵ Facilitation refers to the structures and procedures supporting the IKT process. Much of what has already been discussed is involved in facilitation. Organizations support the conduct of collaborative research by providing incentives and motivation for project participants. A key element of facilitation is the concept of facilitative leadership. Teams are headed by individuals who possess credibility both internal and external to the organization. This assists in promoting more involvement.⁵ The interprofessional team was developed by having members nominated for the partnership, thereby incorporating members who were considered credible by the rest of the organization.

End-of-grant knowledge translation

End-of-grant knowledge translation involves the designing and implementing of strategies focused on the dissemination, diffusion and application of research findings.⁴ It is essential for knowledge translation projects to have an end-of-grant knowledge translation plan in place, allowing end-users to be aware of research findings.¹¹ End-of-grant knowledge translation activities can consist of dissemination techniques such as publications and presentations, aimed towards increasing knowledge of research. Alternately, more intensive application techniques (workshops, tool development) can be used, aimed towards increasing and improving the application of research findings.¹²

End-of-grant knowledge translation activities should consist of more intensive methods if end-users are from outside the research community. Seventy-five percent of public health researchers believe tailoring dissemination to non-academic audiences is essential. Publication language should be adapted to be clear and simple for the audience. However, commonly dissemination is done through academic journals and academic conferences and less frequently through methods such as workshops, face-to-face meetings and media. Decisions about knowledge translation activities should be backed with research and evidence regarding the media and formats best suited for target audiences. However, are

Through the use of a framework such as the Exploration, Preparation, Implementation and Sustainment (EPIS) model, which describes the critical elements of implementation plans, ¹⁴ an effective plan can be created. ¹⁵ The model considers the internal and external contexts influencing implementation, in addition to promoting the continued evaluation of implementations. ¹⁴

In *exploration*, the target audience(s) of the implementation are decided. These audiences include stakeholders not engaged in the IKT project.^{4,16} Their needs are identified to explore their economical and clinical environment, the issues they face with the potential implementation of the IKT findings and the resources they require for successful implementation.¹⁴ It is in this phase that the implementation plan begins to form.¹⁷ This phase was assisted by the inclusion of clinicians embedded in the implementation sites on the research team in the case. Their involvement allowed the research team to identify barriers to implementation, allowing the team to address them in the next phase. The team also communicated with the implementation sites ensuring they were willing and ready to implement the MND into their practice.⁶

The second phase, *preparation*, involves identifying the goals of the end-of-knowledge translation plan, whether it be to try to increase knowledge, change/inform practice and policy or inform future research. 12 These goals may differ depending on the intended audience and their circumstances. Different stakeholders play different roles within the knowledge translation process and defining unique goals for each allows for targeted knowledge translation strategies. ^{16,18} Here a model such as the Lavis model can be used to make key decisions about the knowledge translation process. ¹⁹ The model asks five key questions to prepare researchers for successful knowledge translation. The first question, who should knowledge be translated to, would already have been answered in the exploration phase of the EPIS model. The model requires researchers to take into account the context of knowledge use and prioritize essential knowledge. 18 It questions what knowledge should be translated. 19 Essential findings must be prioritized for effective knowledge translation. ¹⁸ After these aspects of the end-of-grant knowledge translation plan are established, researchers must answer who should translate knowledge and what expertise is required for successful knowledge translation. ¹⁹ Based on the resources available (budget, time, etc.) and the decided goals, appropriate knowledge translation strategies to use are determined.^{4,20} These strategies may involve the utilization of resources such as knowledge champions and knowledge brokers. 4,21 In addition, based on this information the research team will answer: how should knowledge be translated?¹⁹ Through this, the team will determine what knowledge translation activities (workshops, written material, etc.) will be involved in making the implementation successful.¹⁷

The next stage of the EPIS model, *implementation*, involves recruiting the needed expertise such as knowledge brokers, community champions, consultants, etc. and utilizing the decided knowledge translation strategies to implement the findings or intervention.²² The last step is *sustainment*, which is necessary to ensure practice/knowledge changes can be continued. The research team determines the ongoing needs of the implementation sites while also monitoring intervention outcomes.¹⁷

The development committee in the case study developed an implementation plan, defining the specific goals, one of which was to increase knowledge and uptake of the MND. They used strategies targeted to the specific audiences involved, including briefing notes, targeted messaging and training sessions to communicate with end-users at multiple levels, depending on the unique goals and expertise they possess. The team also utilized a knowledge champion, though it is not clear how significant their role was in the implementation stage of the project. The team struggled in achieving wide clinical uptake due to end-users not feeling comfortable with the development process of the MND. Several end-users believed that the MND was developed with little clinician input; however, this was not the case. While the team used effective knowledge translation activities to target dissemination efforts to specific audiences, because the IKT process was not transparent to end-users, clinical uptake was affected. It should be noted that for the sites where the MND was implemented, statistically significant improvements were recorded for 67% of the key performance indicators. The project team would benefit from the IKT process being more transparent to end-users. A key method to do this may be through the use of intermediaries such as knowledge brokers.

Utilizing knowledge brokers effectively

Knowledge brokers act as intermediaries between knowledge producers and knowledge users aiming to aid in the creation, use and sharing of meaningful knowledge.^{23–25} They play a key role in increasing

knowledge and the promotion of evidence-informed decision-making²⁴ by assisting in the identification of issues and information needs of relevant stakeholders, the linking of evidence producers with evidence users, and facilitating access to resources and research.²⁶ In the context of dissemination, knowledge brokers have important roles throughout the process, allowing for successful uptake and practice changes.²⁴ However, their role extends past just knowledge dissemination. Knowledge brokering focuses on encouraging more interactive practices, facilitating IKT processes.²⁷ They assist in enabling two-way communication between knowledge producers and knowledge users.²⁷ The role of a knowledge broker within a project is dynamic²⁸ and can change throughout the lifecycle of the project.

The interprofessional team in the case study faced significant issues in achieving consensus, with one of the key reasons identified being perceived power imbalances. Effective knowledge brokering would be beneficial to the team and assist in dealing with such issues.

The professional environments of researchers, clinicians and health-care managers differ from one another. Researchers are trained to view and analyze information on a population level compared to health-care professionals who often think at a more individual or patient level. Clinicians often fail to consider limitations of data sources and research methods, while on the other hand, researchers often neglect the multifaceted nature of clinical care.²⁷ A knowledge broker can help mediate some of these conflicts; however, they must stay cognizant of these factors as well.

It is important to include groups not directly involved in decision-making in the IKT process.² Knowledge brokering allows less powerful groups to share ideas and make changes.²⁹ However, knowledge brokering can be affected by power imbalances themselves. The health-care field is especially susceptible to imbalanced power structures due to clinicians being the accepted dominant group. This group reinforces institutionalized power structures.²⁹ Social actors such as knowledge brokers may be less willing and able to broker knowledge due to such differences in power. A key technique to deal with this is through the use of internal knowledge brokering.²⁹

Traditionally, knowledge brokering entails external knowledge brokering, consisting of the brokering of formal, codified knowledge from outside of the organization by individuals such as consultants or liaisons.²⁹ On the other hand, internal knowledge brokering is the brokering of tacit knowledge within the organization by individuals or organizations, originating from the collective practice.²⁹ Such brokering often goes unnoticed as it is an element of day-to-day practice.^{30,31} Knowledge brokers coming from a strong research culture may not be well equipped to understand the specific contexts and settings of implementation sites and clinical practice.²⁴ The brokering of tacit knowledge is critical for the development of research questions and the targeting of knowledge translation strategies²⁷ to ensure the context of the project setting is properly understood. Therefore, it is suggested that internal knowledge brokering is more effective^{24,29} as it involves individuals who share a common language and culture with end-users, allowing for enhanced brokered knowledge. In addition, internal knowledge brokering involves more peer-to-peer interactions, allowing for the brokered knowledge to be credible to relevant end-users.²⁹

Internal knowledge brokering can often be found in inter-organizational information system projects,³² such as in the case. Through the use of a designated internal knowledge brokering professional, many of the issues faced by the project team could have been improved. Involving an internal knowledge brokering professional in the IKT process could have made it more transparent to end-users. End-users uninvolved in the IKT process would have more confidence in the information being shared about the MND and its implementation. A second issue that could be mediated by internal knowledge brokering is the development team's difficulty in achieving consensus. An internal knowledge brokering professional would assist the team in harnessing the expertise of the team, allowing them to appreciate each other's skills and experiences while maintaining effective communication through the facilitation of group discussions and problem-solving sessions.²⁷

However, professionals acting as knowledge brokers have a tendency to shift from facilitating knowledge use and sharing towards actually doing the sharing themselves.³¹ This is especially an issue in projects failing to ensure protected time for knowledge translation work. Knowledge users lose motivation to be involved in implementation activities when they have competing priorities in their own work.³⁰ This is a key concern in the case. The project facilitators did not ensure protected time for IKT work and this could be problematic for the inclusion of an internal knowledge brokering professional.⁶ However, the researchers did identify ensuring protected time for IKT work to be a key recommendation for future IKT projects.

CONCLUSION

Integrated knowledge translation projects, such as in the case, require end-users to be involved throughout the process. This requires end-users to be treated as active agents with an equal role in the development of research and practice changes. Such projects must be mutually beneficial to both knowledge producers and knowledge users, allowing them to be transformative to clinical practice. Integrated knowledge translation projects require support from involved organizations and leadership. It is as important to involve end-users in the implementation of IKT projects to ensure they have confidence in the translated knowledge. This requires a well-developed end-of-grant knowledge translation plan targeted towards key audiences, taking end-users' needs into account. End-user involvement can be aided by internal knowledge brokering, knowledge brokered by individuals sharing a language and culture with end-users. The case performed some of these elements excellently, however, struggled with other elements and could have improved by digging deeper into these themes.

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Creating and implementing a patient decision aid to assist implantable cardioverter-defibrillator replacement shared decision-making

A case note on:

Lewis KB, Stacey D, Carroll SL, Birnie D, for the ICD replacement patient decision aid study team. Development of a patient decision aid to accept or decline implantable cardioverter-defibrillator replacement: An example of integrated knowledge translation in PhD research. In: Kothari A, McCutcheon C, Boland L, Graham ID, editors. *How We Work Together: The Integrated Knowledge Translation Casebook. Volume 2.* Ottawa, ON: Integrated Knowledge Translation Research Network. 2020; p. 7-9. <u>Available here</u>.

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SUMMARY OF CASE

An implantable cardioverter-defibrillator (ICD) is a small device containing technology that monitors heart rhythm and, when necessary, generates an electrical shock to restore normal heart rate and rhythm. As a result, ICDs are often implanted for treatment of sudden cardiac arrest. Even though ICDs can be potentially life-saving, they can also cause a major change to lifestyle. This is because as a result of battery life and normal functioning, surgical ICD replacement is required every five to seven years. Despite the magnitude of importance and life-altering nature of ICDs, until the time of this study, patients automatically received replacements without any discussion regarding whether or not it is the best option. For many reasons, ICD replacement decisions should be a collaborative process between physicians and patients; for example, the pros and cons of having them replaced may be viewed differently by different patients or viewed differently by the same patients over time. Researchers in this study indicated that, due to these reasons, ICD replacement decisions should be collaborative; a process known as shared decision-making.

In the case, researchers decided that the development and implementation of a patient decision aid (PDA) was the best strategy to facilitate shared decision-making. O'Connor and Jacobsen note that the Cochrane Collaboration defines PDAs as "interventions designed to help people make specific and deliberative choices among options by providing (at the minimum) information on the options and outcomes relevant to the person's health status." Overall, the case presents two problems: creating a comprehensive PDA that includes balanced facts about the situation, treatment options and the benefits and harms of each options, and effectively implementing it into clinical practice.

KNOWLEDGE TRANSLATION THEMES

The first knowledge translation theme revealed in the case involves **identifying and incorporating all relevant stakeholders**. This theme relates to both prongs of the issue, in that you need relevant stakeholders to both create an efficacious and comprehensive PDA and expertly implement it into clinical practice. In order to achieve proper stakeholder involvement and support in the PDA development process, the researchers used an integrated knowledge translation (IKT) strategy known as a steering committee. The multidisciplinary committee included a wide array of stakeholders including the director of arrhythmia service, the ambulatory device clinic nursing manager, a device clinic registered nurse, expert researchers in PDA development, patients who had previously undergone ICD replacement and the spouse of a patient with an ICD.²

The second knowledge translation theme stresses the **importance of feedback**, another known IKT strategy. In the case, once a revised prototype was approved by the steering committee, researchers sought external review and broad end-user feedback on the relevance, usability and implementability of the PDA.² Firstly, for the purposes of feedback, an external review of the PDA format and content was conducted by five cardiac electrophysiologists.² Secondly, for broad end-user feedback, researchers conducted 16 interviews with 18 different stakeholders including registered nurses, cardiac electrophysiologists, advanced practice nurses, palliative care specialists, psychologists, and ICD patients and family members.² At the completion of the feedback interviews, the steering committee met to review and implement the feedback information.²

Lastly, the third knowledge translation theme, which ultimately drives the purpose of the case (creation of the PDA), is the idea of **shared decision-making**. The case outlined three sources that requested that ICD replacement decision-making be shared; patients, clinicians and clinical practice guidelines. Specifically, most patients wished to be more informed and involved in the ICD process and all clinicians agreed that greater patient involvement was needed.² In addition, clinical practice guidelines acknowledged the preference-sensitive nature of ICD treatment and recommended personalized counseling to facilitate shared decision-making when facing ICD-related decisions.²

LEARNING GOALS

Based on the aforementioned knowledge translation themes, there are three learning outcomes that should be derived from this analysis. Firstly, in any study, especially cases involving the creation of PDAs, it is important to identify and involve representatives of all relevant stakeholder groups. Specifically, you should not only include end-users but also those integral to the implementation process. Secondly, understanding the importance of feedback in a project. Lastly, understanding the idea of shared decision-making and how it benefits health care.

ANALYSIS

Involving relevant stakeholders

Stakeholders can be defined as individuals, organizations or communities that have a direct interest in the process and outcomes of a project, research or policy endeavor.⁴ The incorporation and involvement of these groups in research is supported by the literature. For example, Babbie says that stakeholder involvement improves the integrity of the research, in that public involvement and review can improve

validity, clarity and appropriateness.⁵ Patton argues that the utilization of stakeholders ensures the quality of the results for managers and stakeholders.⁶ In addition, Charles, Schalm and Semradek explain that it provides experiential knowledge related to the research outcome.⁷ Lastly, Cottrell et al. note that it helps anticipate controversy and improve relevance.⁸ Overall, stakeholder engagement is being increasingly promoted across boards of health research funding organizations and by many researchers themselves as an important pathway to achieving impact.⁹ On the other hand, stakeholder identification is a dynamic and sometimes difficult process, and the influence of stakeholders may not become evident until later in the project.¹⁰

Despite the fact that stakeholder identification can be such a difficult process, it is surprising how few strategies or frameworks exist to aid stakeholder identification in the research setting. After an extensive literature review on the topic of stakeholders, it is apparent that stakeholder identification often is, and should be, the first step in stakeholder engagement, but there is very little evidence to inform how to achieve this. The definitions of stakeholders, exemplified by the one provided in this analysis, are often broad and describe stakeholders as essentially anyone one is affected by the research outcome. Additionally, the literature often describes the stakeholder identification process as a brainstorming session regarding who researchers believe will be affected and who they feel they could involve. For example, in *Project stakeholder management in the clinical research environment: How to do it right*, Pandi-Perumal et al. indicate that stakeholder identification entails identifying all people or organizations impacted by the project and documenting relevant information regarding their interests, expectations, involvement and influence on project success, ¹⁰ but there is no information on how to do this. I believe this creates the possibility that not all relevant stakeholders are identified and/or involved as much as they should be.

Relating back to the case, for the creation and potential implementation of the PDA, researchers enlisted a multidisciplinary team in the form of a steering committee that consisted of not only end-users but those privy to the implementation context including: the director of arrhythmia service, the ambulatory device clinic nursing manager, a device clinic registered nurse, expert researchers in PDA development, patients who had previously undergone ICD replacement and the spouse of a patient with an ICD.² The steering committee met twice in person with email and telephone communications in between.² During the meetings, stakeholders shared ideas on PDA format, content, presentation of probabilities, potential distribution plans and the interview guide in preparation for broader end-user engagement.² Additionally, more of which will be described in the feedback section of this analysis, researchers sought the help of a broad range of stakeholders to complete an external review and end-user interviews for the purposes of feedback information.

Considering the literature is scarce on providing evidence on how to identify all relevant stakeholders, I believe the researchers did great work in this regard and made a lot of effort to create a diverse steering committee. The case indicated that including different workers from the setting in which the PDA was to be implemented provided great insight into the clinic workflows and provided expertise on the context.² For example, consulting the director of the arrhythmia service and the ambulatory device clinic nursing manager was important considering their ability to influence the integration of implementing the PDA in the clinical work environment.² In addition, consulting patients and family members also provided

important insights.² Even though extensive measures were put in place to incorporate all relevant stakeholders, the steering committee indicated that their contributions may not have fully represented all stakeholders.² To compensate, researchers interviewed additional patients and family members as part of the broad end-user consultations.²

Overall, I believe that a sufficient effort was made to identify all relevant stakeholders and this contributed to some of the beneficial outcomes previously discussed. This is reflective of the fact that a preliminary evaluation of the PDA indicated that it was an intervention feasible for delivery and that endusers utilized the PDA as intended.² In addition, it led to better knowledge and had the potential to improve ICD replacement decision quality.²

The significance of feedback

Hattie and Timperley define feedback as information provided by an agent regarding aspects of one's performance or understanding.¹¹ This definition can be applied to the case, in that the PDA represents performance. As a whole, there is little research pertaining to the effects of feedback in the research setting or in the process of creating a PDA, but there is plenty of evidence from other disciplines indicating its' benefits.

For example, in the setting of medical care, an approach called patient-focused care provides clinicians with direct feedback regarding a patient's health status and relative progress in therapy. ¹² A study examining this approach found that providing clinicians with direct feedback regarding patients' health significantly improved health outcomes, especially for patients who were struggling with their therapy. ¹²

In addition to patient-focused care, there is an abundance of evidence indicating the benefits of feedback in the education setting. According to Al-Bashir et al., feedback is considered as a vital approach to facilitate students' development as independent learners in order to monitor, evaluate and regulate their own learning. This sentiment is acknowledged and verified by the United Kingdom and Australian educational bodies. Feedback can be beneficial in the educational setting because students can provide information to teachers that can then be used to shape their teaching.

Lastly, there is research reflecting that feedback can lead to better performance in the world of sports and athletics. In a study conducted by Randall et al., they found that instantaneous feedback after performing specific athletic performance tests, like vertical and horizontal jumps and timed sprints, led to improvements in these tasks. Additionally, the study suggested that feedback may also be used for applications surrounding meeting performance targets and thresholds. 14

Despite the fact that health care, education, athletics and this case are unrelated, they are connected in that feedback can and is used to improve outcomes, whether that be health results, teaching ability, athletic performance or PDA effectiveness. I believe the researchers in this case made a significant effort to obtain feedback on their PDA prototype making it that much more effective and appropriate.

As previously mentioned, in the case the researchers obtained PDA feedback using two strategies: an external review and broad engagement via interviews.² Firstly, an external review of the PDA content,

including the probabilities of risks and benefits, was conducted by five expert Canadian cardiac electrophysiologists.² After this was completed, they sought feedback in the form of broad end-user engagement interviews - an IKT strategy.² Specifically, they conducted 16 interviews with 18 end-users representing various disciplines and professions.² Included in the interviews were registered nurses, cardiac electrophysiologists, advanced practice nurses, palliative care specialists, psychologists, patients and family members.² In these interviews, end-users were requested to provide feedback on the PDA and how best to implement it.²

This is in line with the International Patient Decision Aid Standards (IPDAS) which indicates that external peer review or critical appraisal by people not involved in the specific PDA is necessary in the process of creating any effective PDA. ¹⁵ This sentiment is echoed by Coulter et al. who stress the importance that PDAs are carefully developed, user tested and open to scrutiny. ¹⁵ Not only did the researchers in this case follow IPDAS guidelines, but there is evidence that they implemented the feedback. The original clinical trial document indicates that the PDA was revised four times between the creation of the first prototype and the release of the final product. ¹⁶ The fact that it was revised multiple times after feedback analysis and that the PDA was successful leads us to believe that the gathered feedback information contributed to the success of the PDA.

Shared decision-making

This is because the overall goal of PDAs are to inform and facilitate the SDM process. This is echoed by O'Connor and Jacobsen who define PDAs as interventions to prepare patients for decision-making about professional care options.³ They even go as far as to call PDAs "shared decision making programs."³ The case indicates that shared decision-making can be facilitated by PDAs as evidence-based tools that present balanced facts about a condition, treatment options and the benefits and harms of each option.² Patient decision aids also allow patients to consider what is important to them, guide them in the decision-making process and help them establish their preferred option.² The overall goal of the case was to use a PDA to shift the current automated approach to a shared decision-making process. The objective to transition ICD decision-making from automatic to a collaborative process is supported by the literature.

For example, in a study conducted by Driever, Stiggelbout and Brand, they found that most physicians preferred shared decision-making over paternalistic decision-making.¹⁷ In addition, essentially all of the physicians who preferred shared decision-making presented different options for treatment.¹⁷ It is not only clinicians who appear to prefer shared decision-making, but patients as well. van der Eijk et al. outline that patients are increasingly becoming more independent and willing to participate in their own lives rather than being passive agents.¹⁸ In terms of health care, they "search the internet for medical information, wish to have open communication channels with their health professionals, and prefer to actively participate in making important medical decisions."¹⁸ This is echoed in the case, which mentions that most of the patients involved wished for more information regarding their decision and increased involvement in the decision-making process.² In addition, all of the clinicians in the case agreed that greater patient involvement at ICD replacement was needed.²

The evidence also suggests that shared decision-making is associated with better health outcomes. For example, Moore and Kaplan state that shared decision-making "may enhance patient-centered care and increase patients' satisfaction, engagement, adherence and ability to self-manage their conditions." In addition, a systematic review conducted by Shay and Elston Lafata mentions that shared decision-making is associated with better patient reports of affective-cognitive outcomes like less decisional conflict. Lastly, Jordan et al. outline that shared decision-making aids in patient comfort and adds trust between patients and clinicians. ²¹

Despite the clear advantages of shared decision-making, the implementation of this idea can come with a significant amount of barriers. For example, in *Barriers and facilitators of pediatric shared decision-making: A systematic review*, Boland et al. outline a number of barriers that can impede the process of shared decision-making like: perceived lack of options, unacceptable options and affordability by patients, poor quality of information regarding the condition and options, the emotional state of the patient, perception of health status by patients, lack of practitioner shared decision-making skills, power imbalances, lack of time and more.²²

Due to the fact that there are many advantages to shared decision-making, but also many barriers, research conducted to help overcome these barriers and support shared decision-making, like this case, must be appreciated. I believe the PDA created in this case is another step towards improving the health-care setting for clinicians and patients alike.

CONCLUSION

Overall, the goal and motivation of this case was to produce a PDA that would assist in facilitating shared decision-making between clinicians and patients in the ICD replacement decision process. Therefore, the challenges that researchers encountered were not only related to creating an effective and comprehensive PDA, but also implementing it into real clinical settings. To expertly produce and administer the PDA, researchers used two IKT strategies, steering committees and broad engagement via interviews, to ultimately facilitate shared decision-making. At the conclusion of this analysis, readers should have a better understanding of the concepts of stakeholder identification and involvement, feedback in research and shared decision-making. Considering that the case yielded positive results, I believe it could be a stepping stone for creating additional PDAs for other health-related decisions, ultimately shifting the health-care environment to shared decision-making.

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Developing and implementing culturally safe cancer survivorship strategies with First Nations Peoples: A case note analysis

A case note on:

Gifford W, Adams D, Gray E, Montour A, Grandpierre V, Thomas R. Developing and implementing culturally safe cancer survivorship strategies with First Nations Peoples. In: Kothari A, McCutcheon C, Boland L, Graham ID, editors. *How We Work Together: The Integrated Knowledge Translation Casebook. Volume 2.* Ottawa, ON: Integrated Knowledge Translation Research Network. 2020; p. 10-13. <u>Available here.</u>

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SUMMARY OF CASE

Developing and implementing culturally safe cancer survivorship strategies with First Nations Peoples¹ details an integrated knowledge translation (IKT) project done by researchers from the University of Ottawa and Kanohkwa'tsheri:io Health Facility. It serves as a continuation to an earlier publication² completed by members of the same research team in 2018. The primary findings of the initial study² illustrated five themes integral to the unique needs of Indigenous peoples' cancer survivorship. These themes relate to: 1) navigating healthcare; 2) spirituality and ceremony; 3) land, nature and traditional healing; 4) sharing and creating; and 5) finding strength together.² While this study offered insight into current gaps in Indigenous cancer survivorship, it did not provide actionable items to remedy this inequity. With a commitment to explore this issue further, a First Nations community who was involved in the preliminary study – the Mohawk Nation at Akwesane – once again partnered with the research team, with the addition of new colleagues, to pursue this issue further. The knowledge translation issue at hand was to improve cancer survivorship experiences with First Nations people. More specifically, this new team sought to develop, implement and evaluate culturally safe initiatives. Through collaborative and community-based engagement, the team produced dissemination products that directly address cancer survivorship among First Nations people.

KNOWLEDGE TRANSLATION THEMES

Integrated knowledge translation and Indigenous knowledge translation

Integrated knowledge translation (IKT) serves to engage knowledge users with researchers throughout the entire research process.³ While applicable to many KT initiatives, IKT strategies thrive in situations of shared values. Complementary to IKT is Indigenous knowledge translation. Defined by Indigenously led sharing of culturally relevant and useful health information and services to improve Indigenous health status, policy, services, and programs,⁴ it shares many of the same tenets as IKT. With respect to this case, the authors state that "…[our] IKT approach was informed by theoretical underpinnings of Indigenous

knowledge translation...". Evidence of implementing Indigenously informed IKT was present throughout the case.

Cultural safety

While often wrongfully synonymized with cultural awareness and sensitivity, cultural safety as a concept shifts attention away from cultural differences, and towards equitable power relations.⁵ A key component of cultural safety within health contexts is the prioritization of social justice goals as integral, rather than accessory, to health interventions. The notion of cultural safety is the foundation and purpose of this case. The research team prioritized equity and took steps towards creating a culturally safe lens throughout each step of their IKT intervention.

Participatory Action Research with Indigenous communities

From the initial study to this case, Gifford and colleagues prioritized a participatory approach to their work. In particular, they applied a Participatory Action Research (PAR) approach to knowledge creation. PAR is a process that involves researchers and participants working together for the breadth of any project. The intent of a PAR approach is to critically change structures and systems that shape inequities and injustices. The initial study methodology was structured around PAR, and the follow-through is evident in this case. As the context of the case is with Indigenous peoples, a variation of PAR called *Two-Eyed Seeing* was implemented as a way to integrate different ways of knowing and constructing knowledge.

LEARNING GOALS

The crux of this case is to detail the implementation of an IKT initiative. The scope and underpinnings of IKT will be discussed, and the reader will be equipped to apply this in a contextual manner with regards to Indigenous knowledge translation. Next, the concept of cultural safety within the context of knowledge creation will be explored. Readers will be able to recognize its use within this case, as well as understand how to apply it within their own practices. Finally, strategies for PAR will be explained within the context of Indigenous community engagement. Readers will understand these strategies and contrast them to Western ways of thinking and creating collaborative knowledge.

ANALYSIS

Integrated knowledge translation and Indigenous knowledge translation

Knowledge translation takes on many forms and definitions. Given the Canadian context of this case, the definition of knowledge translation procured by the Canadian Institutes of Health Research (CIHR) will inform this case note. While knowledge translation initiatives often implicitly foster ongoing connections with stakeholders and end-users, IKT seeks to do this in a more explicit and meaningful manner. One accepted definition that will be the working definition for this case note is, "integrated knowledge translation is a model of collaborative research, where researchers work with knowledge users who identify a problem and have the authority to implement the research recommendations." Integrated knowledge translation has been said to be a solution to the under-utilization of research, as the process is guided by those who will ultimately benefit from the results. There are numerous cited benefits to taking an IKT approach. Notably, the experiences of involved parties can be equalized, and a new sense of team identity can be created. On the other hand, substantial barriers can be present. Implicit biases may play a

role in how participants view the research and may not view the outcomes as being worthy of their expenditure. Another central principle of IKT is the focus on contextual factors. Since the knowledge translation initiative depends so heavily on the shared responsibilities of all parties, contextual factors are paramount to a smooth working experience. From an equity standpoint, there is potential that not all parties have the required background or infrastructure to be equally as present as others. This can cause a skewed and unjust distribution of ideas. Overall, IKT does serve as a novel method of producing and disseminating knowledge that appreciates the often underutilized opinions of all involved parties.

In the case, the authors only briefly mention that they took an IKT approach for their initiative. There is no explicit mention of any framework or models that they adopted to ensure a truly integrated implementation. However, the combination of Indigenous knowledge translation, cultural safety, and participatory action all culminate to create an integrated system.

The context of this case positions itself within a First Nations community. Given the cultural considerations which must be taken into account, Western ways of knowing and translating knowledge are not the most appropriate. Through various research and storytelling activities, Indigenous knowledge translation has become a valid way of producing information. Indigenous ways of knowing have always existed; however, it is not until recently that they have been deemed acceptable in a post-colonial academic setting. Indigenous knowledge translation—or simply Indigenous knowledge—can be defined as the "Indigenously led sharing of culturally relevant and useful health information and practices, to improve Indigenous health status, policy, services, and programs."

The authors of the case explicitly mention that their "[...] integrated knowledge translation approach was informed by theoretical underpinnings of Indigenous knowledge translation." A notable tenet of Indigenous knowledge is the notion that knowledge is almost always intrinsically connected with action. It is perceived as unwise or selfish to hold knowledge and not put it into action. This challenges the Western epistemological process of knowledge creation where knowledge comes before action. Within the case, the research team and members of the community worked as equals to outline goals and outcomes of the initiative. Because of this, the community members could steer the study towards areas that would result in more meaningful and actionable change. Additionally, this notion of always acting upon knowledge achieves what IKT seeks to do. It ensures that all knowledge being created is purposeful and associated with some type of change.

While Western and Indigenous knowledge translation activities differ in a dichotomous manner, there is common ground. It has been noted that the two can be compatible when the interactions between researcher and subject are defined by the Indigenous context. Throughout the case, while some of the methodology, data collection, and analysis followed a traditionally Western process, the integration of an Indigenous context as well as participation from the community served as a positive collaborative interface. In all, the authors of the case were successful in amalgamating Western IKT with Indigenous knowledge translation. In a sense, not all IKT is Indigenous knowledge, but all Indigenous knowledge is IKT.

Cultural safety

Cultural safety, also referred to as 'culturally safe care,' (CSC) is an evolving concept that originated from New Zealand in the 1980s. ¹¹ The Indigenous Maori people expressed to healthcare providers their need for care delivery that consciously responded to historical injustices faced as a people. ¹² These roots shaped the Western understanding of cultural safety and how to apply it into practice. Cultural safety was introduced into Western public health and academic circles in the late 1980s and early 1990s. ¹¹ While the idea of cultural safety and its integration into health education have been met with immense criticism, the case attempts to embrace it as a tool for combatting inequities. Although there is not one agreed upon definition, health equity researchers have come to define culturally safe care as "[CSC] moves beyond culturally sensitive approaches to explicitly address inequitable power relations, racism, discrimination, and ongoing efforts of historical and current inequities within health care encounters." ⁵ The core of culturally safe care is not to treat individuals based on their ethnic identity, but rather to focus on experiences of oppression as a means to address issues in health equity. ¹²

To further distinguish cultural safety from other related terms, Ramsden set out a continuum of care framework which has been widely used since its establishment. 12,13 Here, its shown that cultural safety begins with cultural awareness, leading to cultural sensitivity, and finally resulting in cultural safety as an outcome. 13 The first step of cultural awareness often involves education to expose the learner to rituals and practices, without delving deep into the emotional, social, economic and political contexts. Second, cultural sensitivity builds on the first step and involves self-reflection to uncover the legitimacy of difference and how their own situation of power has impacts on others. Finally, cultural safety is realized when those on the receiving end of care determine that what they have received is safe. 14,13 Though Ramsden's work was rooted primarily in midwifery and nursing educational settings, health-equity-oriented researchers have transformed these terms into practice. While it may be difficult to fully grasp the concept of cultural safety through definitions, recent work in equity-oriented healthcare has identified ways of making these concepts actionable.

As mentioned by the National Aboriginal Health Organization, one of the key elements of cultural safety is the process of gaining and establishing trust between the provider and patient. The case identifies that "trust and respect were central to establishing the IKT partnership." While this trusting relationship was clearly evident in the case, Gifford and colleagues do mention that much of the trust-building was done during prior studies. The precursors to the IKT initiative saw a large emphasis on relationship-building between the researchers and community members. One of the ways in which trusting relationships were built was through the establishment of an Advisory Group. While this will be spoken about at more length during the Participatory Action Research thematic analysis, it served as a way to gain the trust of prominent members of the Indigenous community. The research team notes that they recognized the importance of building and maintaining trusting relationships, and allowed for sufficient time while balancing costs to ensure that it remained at the forefront of their work. 1,2

Another instance of applying concepts of cultural safety within the case occurred after establishing trust, and before beginning IKT activities. Gifford notes that during the first meeting, they reviewed previous research outcomes with the community members to discuss culturally safe approaches which could address previously identified experiences. This gave Indigenous community members the space to teach

researchers how to better go about their future interactions. This exchange of knowledge and awareness allowed for an equitable space where all voices were treated as equal.

Efforts to maintain culturally safe practices were seen throughout the communication strategies used by the research team. At the beginning of the study, they allocated a name for the study in Mokawk, *To:sha Enhshatsheira:ron*, which translates to *Don't be shy*. While this may initially appear tokenistic, it aligns itself with practices set out by the National Collaborating Centre for Aboriginal (now 'Indigenous') Health. The NCCAH has identified culture and language to be social determinants of First Nations, Inuit and Métis Health. By establishing a Mohawk name for the study, rather than providing a translation after the fact, Indigenous people and their culture were once again being prioritized.

Further in the study, the research team noted engaging in culturally relevant communications and traditions. These included opening and closing ceremonies before and after meetings, traditional teachers and Elders, talking circles, and storytelling.¹ While at face value each of these could fall under Ramsden's aforementioned cultural awareness, the reasoning and use of them skew more towards cultural safety. Establishing a safe place that is responsive to social and other concerns requires the researcher to "…reflect on their own cultural identity and on their relative power…".¹⁶ This attention to power differentials and not imposing Western ways of knowing onto the group processes indicated a concern for culturally safe practices.

The case did mention that an acknowledgement of the historical trauma of colonization, marginalization, and ongoing racism occurred as part of the trust-building process. However, it was not explicitly stated as being acknowledge as part of the reasoning for adopting and implementing cultural communication. More attention could have been placed on this aspect, and if the Indigenous community members themselves instigated these practices.

Participatory Action Research with Indigenous communities

Participatory Action Research (PAR) is a qualitative methodology that integrates knowledge creation and social action.⁶ It is a dynamic process whereby the direction of a study or research is guided primarily by the participants. Rather than having specific goals set prior to beginning the study, the outcomes are constantly changing depending on what the participants deem to be most effective to creating change.

Before being implemented into this case, Gifford and colleagues used a PAR approach to their initial studies to determine which aspects of cancer survivorship needs were not being met for Indigenous peoples. They began their 2018 study by creating an Advisory Group composed of both prominent and lay-people from Indigenous communities, as well as health care workers from Indigenous settings.² This group directed the research team with regards to methodology, recruitment, and outcomes over the length of their study. This ownership over knowledge production was able to uphold ethical standards, as well as equalize power dynamics. Taking this action can be described as true, rather than token, collaboration.¹⁷ Another example of true collaboration present in this case is through the initiation of the project by former Indigenous participants. They understood the value of the previous research and instigated the knowledge translation initiative seen in the case.

Although the case notes that the research is still underway, another instance of PAR is projected to take place during the evaluation process. Members of the Advisory Group showed a keen interest in continuing to work with the research team when it comes time to evaluate their final deliverables. Disseminating results to both individual participants as well as communities is a key aspect of empowerment.¹⁸

Indigenous researchers have identified the value in using participatory action methodologies within their work. There has been an acknowledgement of how Indigenous knowledge translation ultimately shares many of the same values as participatory methods. Scholars have deemed Participatory Action Research with Indigenous methodologies as 'Two-Eyed Seeing.'^{19,18} This concept arose from a Mi'kmaw Elder, Albert Marshall. To paraphrase Marshall, we should see the strengths of Indigenous ways out of one eye, Western out of the other, and use both eyes together.¹⁹ This approach allows for truly participatory and community-based research to be done with and by Indigenous populations. One aspect of the case that aligns itself with the Two-Eyed Seeing methodology is through the idea of capacity-building. Noted to contain tools, gathering stories, and making meaning, among other concepts, ¹⁸ the case expressed various opportunities for capacity-building among both researchers and participants. While the case did not identify Two-Eyed Seeing as being the Indigenous methodology to inform their studies, it is evident that the research team engaged in both PAR and Indigenous knowledge simultaneously. This resulted in actionable outcomes that will ultimately serve the community who needs and created them.

CONCLUSION

Developing and implementing culturally safe cancer survivorship strategies with First Nations Peoples serves as excellent insight into an integrated Indigenous knowledge translation initiative. It bridges Western ways of knowing and creating knowledge with Indigenous ways of knowing. It does so in a manner that displays the parallels between two worlds that bear little resemblance. This allowed the research team and community to provide actionable outcomes for the research that had previously been done, none of which could have been possible without a culturally safe relationship built upon trust. The research team understood the necessary steps to cultivating culturally safe practices and made conceited efforts to see them through. Throughout the entire research project, the research team identified participatory action within the Indigenous communities as paramount. Having Indigenous people be the ones who identify, guide, and contribute to the research allows for an equitable power distribution within research. The concept of Two-Eyed Seeing sets a framework for future collaborative research to be done between Western and Indigenous people.

As this case deals exclusively with Indigenous and First Nations populations, it was paramount for the research team to account for Indigenous KT, cultural safety, and Indigenous Participatory Action Research throughout their studies. As a marginalized and vulnerable population in Canada, efforts towards decolonization need to be conducted in all sectors. With stark health disparities seen in Indigenous communities across the country, health research, implementation, treatment and recovery are all areas in which clinicians can direct their attention to decolonizing practices. Taking cues from this case, what they did well and what could be improved upon, can serve as a learning opportunity for future IKT initiatives within similar settings.

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Promoting health equity through deliberative dialogue

A case note on:

Plamondon KM, Kapiriri L, on behalf of the Canadian Coalition for Global Health Research's Gathering Perspectives studies research teams. Dialogue as a catalyst for equity-centred research: The Canadian Coalition for Global Health Research's Gathering Perspectives studies. In: Kothari A, McCutcheon C, Boland L, Graham ID, editors. *How We Work Together: The Integrated Knowledge Translation Casebook. Volume 2*. Ottawa, ON: Integrated Knowledge Translation Research Network. 2020; p. 14-18. <u>Available here</u>.

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SUMMARY OF CASE

The Canadian Coalition for Global Health Research (CCGHR) is a knowledge network promoting equity in health production and use of knowledge. ^{1,2} It is composed of global health students, researchers and practitioners at institutions and non-governmental organizations (NGOs) across Canada and globally. Members share a common interest in using research to strengthen health systems and contribute to achieving health equity worldwide. ¹

Health equity is a principle that implies everyone should have a fair opportunity to attain their full health potential and that no one should be disadvantaged from achieving this potential.³ There is strong evidence that the unfair advantages and disadvantages in the global distribution of power, wealth and resources are the root cause of health inequity.¹ The case focuses on the CCGHR's Gathering Perspectives studies, which began when the CCGHR Policy & Advocacy Program responded to a call from its members to explore the role of research in global health. This call was triggered when health equity was not reflected in a national report by the Canadian Academy of Health Sciences on Canada's contributions to global health.

The CCGHR Policy Influence Program developed the Gathering Perspectives studies to investigate how global health research practices can contribute to challenging, rather than reinforcing, the root causes of inequities, and define what the future of global health research in Canada should be. The studies were guided by integrated knowledge translation activities, framed in the knowledge-to-action cycle. A series of deliberative dialogues sessions were held and students, researchers, funders, policy makers, administrators, and practitioners who self-identified as being 'involved' in global health research were invited to participate. Overall 18 deliberative dialogue sessions were held in two series over two consecutive years. After integrating the information, the research team was able to develop the CCGHR Principles for Global Health Research.

KNOWLEDGE TRANSLATION THEMES

Through examination of activities and practices outlined in the case, three knowledge translation themes will be discussed in this case note. These themes include integrated knowledge translation, deliberative dialogue, and equity-focused knowledge translation.

Integrated knowledge translation (IKT) is a model of collaborative research, where researchers work with knowledge users who identify a problem and have the authority to implement the research recommendations.⁴ IKT activities are dynamic and highly influenced by the complex context within which decisions are being made.⁵ In the case of the Gathering Perspectives studies, the research team was able to apply appropriate integrated knowledge translations activities to develop strong relationships with stakeholders and engage them in appreciative inquiry and critical pedagogies.

Deliberative dialogue was the central IKT activity used in this case. Deliberative dialogue is a method for bringing people together to cooperatively discuss a possible future, informed by what is known about something of importance to a community. Key outputs of deliberative dialogue are often capacity building and mutual understanding. In the Gathering Perspectives studies deliberative dialogue was used to develop a common understanding of how global health research *should* be done in Canada and strengthen capacity among CCGHR members to engage in equity-focused knowledge translation.

The aim of **equity-focused knowledge translation** is to enhance community effectiveness and promote health equity.⁸ In the case, 18 dialogues including more than 350 people were held across Canada and complemented by a series of online open forums accessed by people around the world to generate greater inclusion and equity in this knowledge translation process. Despite the lack of strong frameworks for equity-focused knowledge translation,⁹ the Gathering Perspectives research team was able to incorporate some elements for promoting equity in the study.

LEARNING GOALS

Through the analysis in this case note, readers will gain an understanding about the importance of maintaining ongoing dynamic relationships to facilitate integrated knowledge translation; learn how deliberative dialogue can be used to develop mutual understandings between diverse groups; and explore frameworks for equity-focused knowledge translation and understand how elements can be incorporated in integrated knowledge translation practices.

ANALYSIS

Integrated knowledge translation

Integrated knowledge translation activities, guided by the knowledge-to-action cycle, were at the foundation of the Gathering Perspectives studies. In this case the decision makers included students, researchers, and practitioners who are involved with global health research. These individuals are tasked with making decisions about which research questions they explore, how they develop their study design and research practices, as well as knowledge translation activities. Since the aim of the Gathering Perspectives studies was to develop a framework for how Canadians should be engaging in the field of global health, considering the literature on integrated knowledge translation, 4,5,10-13 it was integral that these decision makers be involved in the study. Taking this into account the research team involved

participants from the initiation of the study, enabling them to shape the entire research process from study design to dissemination.

Other factors that facilitate successful integrated knowledge translation include interaction at meetings; joint undertaking of research; development of guidelines¹³; and the research team mention they guided interaction at meetings by drawing upon principles of appreciative inquiry and the reflexive nature of critical pedagogies.^{1,14} Appreciative inquiry is an integrated knowledge translation intervention with a unique focus on highlighting organizational strengths, rather than weaknesses to enhance practice.¹⁵ The appreciative inquiry process consists of the 4-D cycle: Discovery, Dream, Design, and Destiny.^{15,16} The Gathering Perspective research team's actions seem consistent with this cycle.

The national report by the Canadian Academy of Health Sciences on Canada's contributions to global health provided the foundation of the discovery phase, and they led the participants in the first series of dialogue sessions to envision as people with a shared interest in global health research, how they should engage in the field. Through this engagement, decision makers were able to express their ideas and identify opportunities for action for the research team. Participants identified the need for a set of guiding standards in the field of global health research. The research team developed the CCGHR Principles for Global Health Research, which could be considered a tool to help sustain the change created through the study.

The Gathering Perspectives studies research teams also mention they took time to reconnect with stakeholders like the CCGHR Board and general membership, funding agencies, senior researchers and international partners to get their insight on what was learned from the studies and what kinds of knowledge products would be most impactful. By re-engaging key decision makers, and holding sequential series of dialogue sessions, the researchers were able to maintain ongoing relationships with decision makers, which is a key factor of integrated knowledge translation.¹⁰

These approaches to integrated knowledge translation seem to be consistent with previously suggested best practices. ^{4,5,10-16} By involving major stakeholders from problem definition through to study design, analysis, and dissemination, the research teams were able to successfully adopt an integrated knowledge translation approach for their research program.

Deliberative dialogue

Deliberative dialogue is a knowledge translation method for bringing people together to co-create ideas of possible futures through discussion.⁶ Deliberative dialogue sessions are guided by considering research evidence and other knowledge in the context of the unique experiences of the people who are gathered.⁷ This method of bringing stakeholders together is suggested to be a powerful tool for generating mutual understanding and capacity building.^{6,7}

As previously mentioned, the central aim of the Gathering Perspectives studies was to understand the role of research in global health and come to an understanding about how Canadians should be engaging in the field. In order to consider all perspectives, students, researchers, funders, policy makers, administrators, and practitioners who self-identified as being 'involved' in global health were invited to participate in the

study. Among various stakeholders there are often differences in the motivations, interests, values and beliefs underlying their involvement.

Considering the overall goal of the studies and the challenges presented, the research team appropriately chose deliberative dialogue as the main integrated knowledge translation activity. ¹⁷⁻¹⁹ The research team also showed consideration for the key features that facilitate effective deliberative dialogue as stated in the literature. ^{6,7,17-19} Boyko et al. (2012) identified key features of deliberative dialogue including an appropriate meeting environment, an appropriate mix of participants, and an appropriate use of research evidence.

Prior to the initiation of the deliberative dialogue sessions, the research team published *A Call for Dialogue on the Role of Research in a Canadian Vision of Global Health*.² In this report they transparently report the study purpose and design, and the timeliness of the issue, which are key issues to consider for facilitating a supportive meeting. The research team also mention they conducted an in-depth stakeholder analysis to identify all relevant perspectives and engage an appropriate mix of participants. The Canadian Academy of Health Sciences report on Canada's strategic role and contributions to global health, which triggered the study,²⁰ contributed to the research evidence along with the tacit knowledge that participants shared.

The research team established the focus of the first series of deliberative dialogue sessions to generate collective insights about foundational values guiding how people should engage in the field of global health research. This method of guiding the conversation aligns with another feature of deliberative dialogue – enabling structured, future-focused conversations⁷. Additionally, participants in the dialogue sessions were able discuss options for addressing the problem, and present calls for action, which is a feature of deliberative dialogue that participants often value¹⁷.

The development and widespread adoption of the CCGHR Principles for Global Health Research¹ exemplifies the utility of deliberative dialogue for capacity building and as an integrated knowledge translation approach.

Equity-focused knowledge translation

The final knowledge translation issue considered in this case is equity-focused knowledge translation. It is important to not only consider promoting equity in research, but also in knowledge translation practices.

Overall, however, there is a lack of integration of health equity-related concepts in models of knowledge translation or knowledge-to-action. A review by Davidson et al. found that of the 48 knowledge-to-action frameworks they identified, only six models scored between eight and 10, with no model scoring the maximum 12 points on the health equity support rubric. Elements of the health equity support rubric include explicit focus on equity or related values, inclusive conceptualization of knowledge, stakeholder engagement, explicit focus on interactions across jurisdictions or sectors, context emphasized, and applied pro-active, problem solving. Models for knowledge translation that are intended to explicitly promote equity, such as the cascade for equity-oriented knowledge translation by Tugwell et al. and the Translational Research Framework to Address Health Disparities by Fleming et al., and the

mentioning the importance of stakeholder engagement and focusing on interactions across sectors. Considering the elements from the health equity support rubric against the methods used in the Gathering Perspectives studies, it is clear that the research team actively engaged in opportunities to incorporate equity in the study.

With the explicit goal of understanding how research can challenge, rather than reinforce the root cause of health inequities, the research team sought diverse perspectives and sufficient representation from across the spectrum of those involved in global health research.¹ As mentioned earlier, prior to the initiation of the study, the research team stated they conducted an in-depth stakeholder analysis and invited those identified to participate in the deliberative dialogue sessions, supporting their commitment to stakeholder engagement.^{23,24}

Additionally by focusing on deliberative dialogue as the central integrated knowledge translation method, they promoted an inclusive method of conceptualizing knowledge, as deliberative dialogue emphasizes sharing interpretations of the implications and contextualized meaning of synthesized evidence, rather than attempting to 'extract' data from participants. ¹⁹ The case also mentions the deliberative dialogue method was chosen to honour the diversity among participants while inviting collective reflection about aspirational ideals of the future of global health.

Although it seems that the research team may not have applied pro-active problem solving in this case, following the first series of dialogue sessions, the team appropriately responded to the calls for action from study participants and CCGHR members overall. Furthermore, although initially developed to guide equity-focused research, CCGHR Principles for Global Health Research can also serve as a broadly relevant framework to integrated equity considerations into knowledge translation, and practices/activities as well.²¹

Plamondon suggests that work intended to advance health equity may encounter the same power structures that are known to cause health inequity. It seems, however, that the actions taken by the research team helped to illuminate how global health research should be conducted, could be considered a more productive action to challenge health inequities.²⁶

CONCLUSION

In the field of global health research, considering the differences in the motivations, interests, values and beliefs among stakeholders, the Gathering Perspectives studies research team appropriately adopted an integrated knowledge translation approach. Grounding the Gathering Perspectives studies in an integrated knowledge translation approach was integral to the adoption of the CCGHR's Principles for Global Health Research. Specifically, with the goal of framing how Canadians should be engaging in the field of global health research, using deliberative dialogue as the central method enabled capacity building and stakeholders to come to mutual understandings. Despite the lack of integration of equity promotion in many knowledge translation frameworks, the research team was able to integrate elements to support equity in this case. Overall, the Canadian Coalition for Global Health Research's Gathering Perspectives studies effectively incorporated the current research evidence on various knowledge translation issues and produced meaningful dialogue and effective equity-promoting tools.

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Ready to go: A critical look into the approach of supporting the development of a funding application to explore patient engagement in Canadian circulatory and respiratory diseases research

A case note on:

Banner DJ, Graham ID, Bains M, Carroll S, Aaron S, Healey J, Stewart D, Tang A, Runte M, McGavin C, Kandola DK. Ready to go: Using an integrated knowledge translation approach to support the development of a funding application to explore patient engagement in Canadian circulatory and respiratory diseases research. In: Kothari A, McCutcheon C, Boland L, Graham ID, editors. *How We Work Together: The Integrated Knowledge Translation Casebook. Volume 2.* Ottawa, ON: Integrated Knowledge Translation Research Network. 2020; p. 19-22. <u>Available here</u>.

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SUMMARY OF CASE

Healthcare organizations face many challenges developing and implementing evidence-based services to improve practice and health outcomes for circulatory and respiratory diseases. In response, they have shifted towards engaging more patients in the research process to improve the impact and relevance of research. This includes involving patients for their insights and partnerships to co-create and make decisions in the research process. The case by Banner et al. illustrates the use of an integrated knowledge translation (IKT) approach to foster early partnerships with researchers and knowledge users to support the development of a grant proposal. The goal of this research is to identify gaps, priorities, and opportunities for future patient-oriented research in circulatory and respiratory diseases.

Planning and developing the research plan took place to foster early collaborations between researchers and knowledge end-users. By research scientists and knowledge users (network leaders and patients) engaging in teleconference meetings, roles for collaboration and common goals were made. After 20 meetings, the general consensus was to apply for a Canadian Institutes of Health Research (CIHR) Planning and Dissemination Grant to provide the financial support needed. Banner et al.'s IKT approach led to two successful grant proposals, which significantly impacted the team's ability to create larger-scale research. This program led to healthcare research within different healthcare networks to advance the science of patient engagement and the uptake of evidence that is responsive to the needs, values and priorities of patients.

KNOWLEDGE TRANSLATION THEMES

This case was successful due to the researchers' ability to engage with end-users and establish early partnerships with them throughout the application process. In this case, the theme of **patient engagement** led the team to create a more impactful grant application that could directly increase patient health

outcomes as they involved patients as co-authors. Their first knowledge translation (KT) theme of incorporating diverse end-users, specifically patients, within the research project led to their success. While there is a surge of interest in engaging patients within a KT research project, there is some variation in how this can occur. Their second IKT theme was **establishing early partnerships** in the research process. In the literature, this is as a relatively new strategy in IKT that has shown potential benefits. Specifically, in this case, the research team established early partnerships with the network leaders to create a plan and assign individual roles. However, the overall task of engaging end-users, both patients and network leaders, can be challenging. While the researchers in the case took on this role, facilitating and disseminating with network leaders is not the typical role of a researcher. Instead, the researchers could hire a knowledge broker on the team. **Knowledge brokers** are mediators during the research process and can ease interactions between different team members so that they are able to better understand each other's goals and professional culture.

Understanding how the researchers implemented these themes will help us to better understand how it led to their success. This leads us to the following learning goals.

LEARNING GOALS

- 1. To understand patient engagement in developing research that reflects the needs and priorities of patients.
- 2. To understand how early partnerships between researchers and end-users creates a successful research project.
- 3. To understand the role of a knowledge broker in an IKT research approach.

ANALYSIS

Patient engagement

According to the CIHR, patient-oriented research refers to the continuum of research that engages patients as partners, and focuses on patient-identified priorities to improve outcomes. When analyzing the case, we see the authors implemented a strong framework for incorporating end-users into the grant. This led to the idea for the first KT theme of patient engagement, resulting in Banner et al. creating a more impactful grant application, which directly increased patient health outcomes. Through adopting principles of patient engagement, we see that there is facilitation through inclusiveness, support and commitment to be co-creators of knowledge. This, along with allowing the patients to be co-authors and recognizing their contributions, aided in the success of the grant.

When further exploring the KT literature, we see that patient-oriented research approaches are a way to develop research that tackles ongoing gaps in practice and reflects the priorities of patients and their health. However, patient engagement varies in KT and IKT approaches. In KT, patients are used mostly for end-of-grant applications, while in IKT, patients are required collectively across the research process to identify key priorities and develop the plan.³ To involve patients in the entire project, researchers need to provide strong support for patients and encourage their involvement in the research process. In a scoping review by Manafo et al., the authors depict that there are many positives outcomes that can occur for research with patient engagement; however, it is the role of the research team to provide the adequate resources for the patients.⁴ This includes engaging patients early on, defining their roles, providing

education, evaluating the engagement levels, etc. Many of these positive strategies can be seen within the case by Banner et al.¹

When further reviewing the literature, we see that many grants for healthcare research stream from CIHR's Strategy for Patient-Oriented Research (SPOR) or the Patient-Centre Outcomes Research Institute (PCORI). These institutes heavily rely on patient engagement being the driver of the research initiative. Furthermore, these institutes heavily fund research initiatives that involve patients in each step of the research, including: the proposal, design, conduct, and dissemination of the project. Successful applicants must also explain why the proposed research question is patient centered and why its answer will be likely to change practice and improve patient outcomes. While this can be a challenging task, these institutes provide many resources and tools, such as frameworks and checklists for researchers to incorporate. These resources aim to provide patients with support from the research team throughout the process and are an additional way for researchers to be accountable of their role. While the case by Banner et al. discusses using patients throughout the research process, using a framework from the SPOR or PCORI guidelines would help the research team really reflect on their engagement strategies and make the team more accountable for their engagement.

A specific example of using the frameworks from PCORI as resources to further enhance patient engagement is a study by Cukor et al.⁶ This study looked at seven different clinically-focused studies on patients with kidney disease that were funded by PCORI. The goal of this study was to understand how the clinical research of kidney diseases can occur by using patient engagement. The results of this paper highlighted that research teams who used PCORI's resources were more successful. Specifically, the PCORI "Engagement Rubric" highlights three key phases of research into which patient input can be incorporated: study design, implementation, and dissemination of the results.^{6,7} Teams that used this framework created stronger proposals which were accommodating of patient engagement throughout the entire research process.

The next steps for Banner et al. would be to use a framework that could further enhance patient engagement, as it would be a more reflective and continuous practice for both researcher and patient. While their current strategy was good, it did limit patient engagement to an extent. Therefore, incorporating resources from funding institutes can aid in the creation of a more rigorous research initiative for both researcher and end-user, and increase patient engagement.

Early partnerships between researchers and end-users

Partnerships between researchers and end-users can vary from policy-makers, managers, clinicians or patients, to co-generate and implement knowledge in a KT or IKT research initiative. When analyzing the case, Banner et al. were successful due to incorporating partnerships between researchers and end-users to facilitate collaboration. The importance of establishing partnerships lies in the timing of when you establish them. In this case, establishing partnerships early on in the research process allowed for assigning roles and deliverables of the grant more successfully. Furthermore, incorporating network leaders early allowed for their feedback and recommendations during the early stages of the proposal. This brings us to the second IKT theme of establishing partnerships early on.

When further exploring the literature, we see the popularity of early partnerships in other IKT initiatives. Since IKT heavily relies on collaboration with many different types of end-users, this theme is often reoccurring within the literature. In a study by Sibbald et al., they investigated the different experiences, barriers and opinions of researchers and end-users that were funded under CIHR's integrated KT funding opportunities to better understand these partnerships. They discovered that partnerships could be categorized into three different types: token for researcher dominant, egalitarian for researcher and knowledge-user lead and asymmetric for researcher lead and some knowledge-user engagement. From the results, we can see that egalitarian research teams communicated early on in the process and tried to keep a wide network of dynamic partners. Throughout the case, Banner et al. led with an egalitarian approach, incorporating a wide network of partners to tackle the grant.

While their egalitarian style was successful, it was not the only concept involved in the theme of early partnerships. Banner et al. also used many forms of communication, such as teleconference meetings to solidify relationships and assign roles early on, followed by many meeting notes and shared documents to solidify common goals and interests. These added to the pillars of developing a strong partnership. These concepts have been further researched in a meta-narrative review by Zych et al., which explored the conceptualization of partnerships. The results showed that IKT partnerships included setting priorities, establishing virtual and physical communication space, clarifying and establishing vision, goals, roles, mission and other project management documents. This resulted in strong facilitators toward partnerships in IKT initiatives.

When further reviewing the literature, we see that CIHR provides resources such as the CIHR Casebook for researchers. This book highlights different strategies that researchers can use and different opinion pieces from previous CIHR winners in different healthcare fields. The casebook highlighted a few strategies that could be useful to the case by Banner et al., including implementing a checklist or working model to record partnerships, making sure to have trust and patience with your partners and constant communication to set goals. One specific case study from the book that relates to the case by Banner et al. is regarding the Alberta Bone and Joint Health Institute. This case created a new model of care for hip and knee replacements by including a team of clinicians, administrators, patients and policy makers. Their success resulted from their communication strategies with partners. They provided workshops early on, communicated positively with the team, and had frequent meetings to ensure success. These workshops allowed training opportunities to allow all partners to gain the same knowledge and experience.

The next steps for Banner et al. would be to include frequent positive communication with the partners early on and introduce workshops. While their current strategy was good, it did limit partnerships to an extent. Therefore, using ideas from the Alberta case could be an additional way to advance the level of establishing partnerships throughout the project.

The role of a knowledge broker

One of the biggest challenges in KT is bringing in a wide array of team members of researchers and endusers to collaborate. This creates challenges as everyone has different levels of knowledge and contributes differently to the research project. Furthermore, not all researchers feel comfortable with approaching partners outside their research network, such as stakeholders or policy-makers, as they may not have the right resources to target them. One strategy that researchers can implement is the use of a knowledge broker to help close this gap. Knowledge brokers can link researchers and end-users by facilitating interaction, so that they are better able to understand each other's goals and professional culture, influence each other's work and forge new partnerships.¹²

When assessing the effectiveness of a knowledge broker, we can look at the systematic review by Bornbaum et al., which discusses the different roles that a knowledge broker can do in a KT project. Knowledge brokers are trained to facilitate collaboration, which can include organizing group forums such as workshops, journal clubs, online forums or committee meetings. They are able to establish communication channels, group discussions and problem solve issues between partners. Furthermore, a knowledge broker is a good resource to help with connecting stakeholders or organizational leaders. They are trained to facilitate and engage others who also share the same common goals and interests in the research project; a task not all researchers may be comfortable doing.

When analyzing the case by Banner et al., the authors did not use a knowledge broker throughout their initiative, which was a limitation. While the authors on the team were experienced and took on the role of facilitating partnerships themselves, it is not always an easy task for researchers. In a study by Knight et al. that investigated the role of a knowledge broker in a grant application process, the findings showed that not all researchers were capable of the role that knowledge brokers can provide. Further, the knowledge brokers were involved in writing parts of the grant application and ensured that network leaders were accountable for their parts of the application. ¹⁴ This is a great strategy for project management in a grant application and could have benefited the case by Banner et al. This would allow them to allocate some of the challenges that come with writing and collaborating with network partners to the knowledge broker, so that they can focus on the parts of the grant that researchers excel in, such as the methodology and study design of the project.

Furthermore, introducing a knowledge broker would also be a good strategy for our second IKT theme of initiating early partnerships. Knowledge brokers are a resource for creating and facilitating workshops, so that network leaders and researchers are on the same knowledge level. This will make the process of working together as a team more efficient. Additionally, they can initiate and approach leaders that researchers may not have all the resources for. Knowledge brokers specialize in engaging with stakeholders and policy-makers, which not all researchers can do. Knowledge brokers have many connections and strategies for engagement so that researchers can focus on other tasks needing to be accomplished for the grant application.

Therefore, while Banner et al. were able to facilitate engagement between network leaders themselves, they were limited, so their next steps should be to hire a knowledge broker. This step should be done in the early stages of the project, before recruiting end-users. Knowledge brokers can strategize with the research team early on to define their role and integrate themselves into the research project, before including patients or stakeholders. This will provide the research team with additional resources that are applicable to the development of the grant.

CONCLUSION

In conclusion, the case study by Banner et al. was a strong example of end-user engagement within a grant application process. There were many strategies that the team used to be successful in winning two different grants. From their research, we learnt:

- 1. Involving patients within the research process allows for a more inclusive grant that is strongly patient-oriented.
- 2. Initiating early partnerships between researchers and end-users allows for the development of a more inclusive research grant.
- 3. Using a knowledge broker can enhance the grant application process for researchers and provides strong project management skills and resources for the team.

Overall, these lessons are versatile and can be implemented in different fields of healthcare research for grant applications.

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Collaboration & communication in the ATTACH project: An integrated knowledge translation initiative

A case note on:

Letourneau N, Donnelly C, Gagnon M, Hart M, Anis L. The Attachment and Child Development (ATTACH) integrated knowledge translation project. In: Kothari A, McCutcheon C, Boland L, Graham ID, editors. *How We Work Together: The Integrated Knowledge Translation Casebook. Volume 2.* Ottawa, ON: Integrated Knowledge Translation Research Network. 2020; p. 23-25. <u>Available here</u>.

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SUMMARY OF CASE

The Attachment and Child Development (ATTACH) project is a reflective function intervention developed for at-risk parents and children struggling with the effects of violence, addiction, and depression. ATTACH is an integrated knowledge translation (IKT) project that obtained funding from the Palix Foundation, the University of Calgary, and PolicyWise. ATTACH was developed based off the findings of the "Brain Story," a toolkit implemented by the Alberta Family Wellness Initiative (AFWI), and aims to educate individuals about neuroscientific evidence regarding the importance of early life experiences for proper brain development. The AFWI funded a research chair in Parent-Infant Mental Health at the University of Calgary, Nicole Letourneau, who collaborated with executive director Carlene Donnelly and her staff of the Calgary Urban Project Society to extend and mobilize these findings to create and implement the ATTACH project.

The Brain Story proposes that early exposure to family violence, addiction, and mental health issues have a negative impact on the development of the child, inhibiting parental sensitivity and responsiveness.¹ This obstructs the development of secure parent-child attachment, which is influenced by parental reflective function.¹ Parental reflective function, the ability to understand the emotions of others, is the construct Letourneau and Donnelly have targeted with the ATTACH project, an intervention aiming to increase the overall responsiveness and sensitivity of at-risk parents towards their children.

KNOWLEDGE TRANSLATION THEMES

From the onset, an evident theme throughout this case was the team's **engagement with community partners**. AFWI collaborated with the Calgary Urban Project Society, a Calgary service agency working directly with families struggling with low-income housing, education and health services. AFWI educated the community on the findings from the Brain Story, extending knowledge to the public and various working professionals including those in government, health and social services and research. The project's engagement with community partners regarding an issue of mutual concern made for an

extremely successful and worthwhile endeavour. A second major theme in this case was **networking**. AFWI bridged connections between the research chair and the community agency, and executive director Carlene Donnelly then introduced other staff members of the Calgary Urban Project Society and Calgary agencies, elevating the success of the project as awareness began to spread. The theme of **effective communication and dissemination** was also reoccurring. The ATTACH project was facilitated by the use of multiple platforms including in-person workshops and presentations, or at a distance through emails and phone calls, extending the reach to a variety of professionals. The team members also held meetings three times per year between the researchers and community service providers to ensure that the needs of the project were being satisfied, and those in research and policy planning were given the option to receive biannual newsletters.

LEARNING GOALS

This paper will discuss three main learning objectives. They will be as follows:

- 1. Involving the community in the decision-making process ensures that the project meets the client needs.
- 2. Networking and fostering connections are essential processes for successful project implementation.
- 3. Effective communication and dissemination strategies ensures that knowledge and information will reach the greatest number of individuals.

ANALYSIS

Engagement with community partners

The literature recognizes the need to engage community partners in the research process, as it has been argued that some research and practice does not properly represent the needs of those who have health concerns, or those who utilize health services.² To better create a sustainable, equitable health system, members of the community need to be involved in its implementation to better reflect the needs of those who utilize the system. Involving community members in the research process helps to fill the research-to-practice gap and has the potential to increase the relevancy and effectiveness of practices.³ Because of their already established background in the healthcare industry and their familiarity with the specified community, community partners are well positioned to assist in project development and translate the study's findings accordingly.³

The Canadian Institutes of Health Research (CIHR) Partnerships Casebook exemplifies various case studies that have undertaken engagement with community partners to better build their projects. The implementation of the Ktunaxa Community Learning Centres (KCLC) in an Indigenous community is one example of a case that engaged with the public from the outset of the project. This ensured that proper respect for Indigenous tradition was upheld throughout its execution and that the community's health needs were appropriately considered. Led by the community, the KCLC preserved traditional forms of knowledge and information specific to Indigenous community contexts, all while providing employment opportunities for the Indigenous peoples. The community-led learning centre also identified community-based health needs through the evaluation of web-based resources. This allowed for the community to contribute to the overall vision and effectiveness of the KCLC for its clientele.

Building off this case, the ATTACH project could have also included patients and families who would be the ones using the intervention to assist in its development. ATTACH did a good job including community partners such as the Calgary Urban Project Society, a service agency that works directly with at-risk families and other community service providers, but did not directly include the voices of the families themselves when it came to developing the intervention to ensure they were reflecting their needs.

Similar to the ATTACH project, the Human Early Learning Partnership (HELP) disseminated knowledge regarding biological, psychological and societal factors that play a role in the development of children.⁴ Similar to ATTACH, HELP's strategy was also to engage local communities alongside the research team to better address research-to-practice gaps and take effective courses of action, ensuring that the knowledge they provided was easily understood and could be easily applied to said community.⁴ Community stakeholders conveyed their knowledge regarding their own children that would benefit from the program, playing an active role in the program's development. The HELP case was a success because community partners were respected when bringing their knowledge to the table, and everyone's strengths combined (community, government, researchers) brought awareness to the importance of early childhood development.⁴ This resulted in the opportunity for more children in the community to succeed. Because the ATTACH project engaged with community partners from the very beginning of the project's development, the project's implementation reflected a mutual desire to address the needs of the project's prospective clientele. In sum, engaging community partners has the potential to increase the validity of practical and experiential knowledge, strengthening egalitarian practices.⁵

Networking

The literature suggests that networking and building alliances is extremely important in constructing successful knowledge translation (KT) practices. Networking can be defined as interconnected groups of individuals who unite because of a common purpose or interest and share a desire to work towards a greater good. Improvement in the healthcare system is extremely dependent on social relations and mutual trust, as this forms the basis for innovation and the development of new ideas. Social interaction between researchers, clinicians, healthcare professionals, individuals in clinical interventions and others has the potential to build the strong networks necessary for successful IKT initiatives. Such connections are of great advantage to IKT as they increase access to different types of knowledge, skill sets, and resources that can enhance the overall performance of an IKT initiative.

Networking is valuable in the field of KT for many reasons. Networks have the power to diversify the healthcare system, disseminate information more effectively, and amplify useful knowledge and expertise that could otherwise be overlooked. Information exchange, brainstorming ways to more effectively bring evidence into practice, and evaluating the overall outcomes of the KT project are all factors that are considered between KT network systems. All of these factors signify the importance of actors and their relationships to effectively mobilize findings between the stakeholders involved in the project. The ATTACH project is an example of an IKT initiative that effectively networked with agencies and staff members to transform the landscape of the project for the greater good of at-risk families based in a community in Calgary, Alberta. The AFWI utilized their connections and networks to implement a strong and diverse team.

New ideas and opinions have the potential to spread more effectively if they are facilitated by opinion leaders. Opinion leaders are individuals who lead and shape the attitudes, beliefs, and behaviours of other people. In public health, opinion leaders are utilized for health promotion efforts, advocate for change, and increase the growth and development of community-based health programs. Often, they possess three main qualities: strong morals and principles, competency and level of skill in their field, and a good size of strong, quality social networks. In the case of the ATTACH project, Carlene Donnelly, executive director at the Calgary Urban Project Society, had established connections with other agencies and leaders that assisted in the development and expansion of the ATTACH project. Donnelly's ability to facilitate social interaction brought immense success for the project, expanding its services into other agencies across the nation of Canada. Opinion leaders like Donnelly are an important conveyer of health information, promote programs and interventions, and facilitate project successes.

The literature suggests that workshops and conferences are an effective method for program promotion and network building.⁴ Events such as these breed numerous opportunities for collaborations amongst diverse disciplines.⁴ In a case study by CIHR, the Down Syndrome Research Foundation was highly successful in part due to liaising at organized workshops and conferences, eventually creating successful affiliations with Simon Fraser University.⁴ The ATTACH project also implemented successful networking consultations such as workshops, presentations, and formalized meetings to disseminate knowledge and foster new relationships amongst stakeholders.

Effective communication & dissemination

Knowledge dissemination is a fundamental strategy in KT. Knowledge dissemination efforts account for everything including the message, the medium, the audience, and the source of the message. The dissemination of health information involves the personalized, targeted distribution of knowledge via specific mediums to a determined audience in the healthcare field. Many methods of knowledge dissemination exist to reach individuals such as policy-makers and other practitioners, including news media outlets, social media platforms, policy briefs, meetings, in-person workshops and seminars. Effective dissemination has the power to influence public awareness of the KT issue, implement more effective use of evidence in practice, and enhance policy reform. The National Institute for Health Research suggests that a good dissemination plan always accounts for the audience, has a good timeline in mind, makes use of resources, and strategizes to ensure that the dissemination of knowledge will be impactful and successful.

Identifying and understanding your target audience is a crucial step to maximize the possibility that information will be accessible and comprehensible. The Agency for Healthcare Research and Quality suggests that using a wide variety of platforms and mediums to communicate the message will ensure that the knowledge will reach more individuals, as well as the probability that the audience will comprehend that information enough to use it.¹¹ Tailoring the message specifically to the audience, such as designing the advertisement to specific subcategories (for example, young adults with children, seniors, sex, race, etc.) and using a narrative that is a testimonial that conveys the gains of the specific project are all useful strategies to consider when disseminating information.¹¹ ATTACH did a particularly good job of doing this – to extend the reach of their knowledge, they utilized multiple platforms to facilitate partner

discussions such as in-person workshops, phone calls, emails and newsletters to communicate knowledge findings and organize the program. This is an important and useful strategy as some people may absorb the information more effectively depending on the platform used.¹⁰

ATTACH also succeeded in maintaining open and frequent communication between themselves and their community. According to Brownson et al., it is essential that frequent communication is upheld in order to share knowledge and to maintain regular contact with those involved in the research process. ATTACH held triannual meetings between the researchers and community stakeholders and invited those involved to receive biannual newsletters to stay up to date with the development of the program and keep in touch. This demonstrates that the ATTACH project utilized effective health communication campaigns even after the project had been developed. Brownson et al. suggest that audience segmentation and strategic marketing is vital for product success – ATTACH ensured that they maintained effective marketing of the intervention by tailoring their message through newsletters to community service providers who are in the position to advocate and promote the program to their clients.

CONCLUSION

Involving community stakeholders in project development, building strong networks, and effectively disseminating knowledge are three extremely important functions within the field of IKT. Engagement with community partners allows for an intervention or service to better reflect the needs of those who will be utilizing it, ensuring that patient needs are met accordingly. Building strong alliances and networks allows for the implementation of new ideas, opportunities, research initiatives, and promotion of the intervention.⁴ Finally, effective communication and dissemination ensures that information and knowledge will reach the greatest number of individuals. All of these strategies were utilized effectively by the team of the ATTACH IKT project.

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The importance of IKT partnerships and producing sustainable research

A case note on:

Poole JC, Pusch D, Dobson KS, Sherren N, Gagnon M, Bergman J. Using an integrated knowledge translation approach to better understand the impacts of adverse childhood experiences among adult primary care patients: The EmbrACE study. In: Kothari A, McCutcheon C, Boland L, Graham ID, editors. *How We Work Together: The Integrated Knowledge Translation Casebook. Volume 2.* Ottawa, ON: Integrated Knowledge Translation Research Network. 2020; p. 26-28. <u>Available here</u>.

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SUMMARY OF CASE

Adverse childhood experiences (ACEs) have been recognized as determinants of poor health for adults but primary care settings do not routinely address them. With approximately 70% of primary care patients reporting a history of ACEs in Alberta, this presents a major problem in current practice. In 2013, a partnership was formed by the EmbrACE Research Team and the Palix Foundation to develop the EmbrACE study in efforts to improve upon the current trauma-informed policies, practices, and programs. The Palix Foundation is a private foundation focused on applied research and knowledge mobilization in the area of the science of early brain development as well as its impact on lifelong health.

The multidisciplinary EmbrACE research team would meet monthly to discuss progress, prioritize, interpret findings, and discuss literature relevant to the study. The invitation was open for the primary care patients to attend these meetings. Focus groups were organized three times a year for the primary care patients. These sessions were implemented to focus on the patients' experience in healthcare settings and get their input on the EmbrACE study materials (i.e., preliminary treatment protocols, questionnaires, recruitment material). The objectives of the EmbrACE study were to identify a clinically validated tool to measure the history of ACEs, to assess relationships between ACEs and health outcomes (i.e., mental illness, chronic disease), and to develop and then test a clinical treatment program designed to improve health outcomes for patients in primary care settings with a history of ACEs. These three phases of the EmbrACE study were completed in 2014, 2016, and 2019, respectively. Each phase of the study was conducted in primary care settings in Alberta, Canada.¹

KNOWLEDGE TRANSLATION THEMES

IKT: Developing sustainable change

An IKT approach allows for expertise from various disciplines to collaborate so more relevant research questions can be addressed, enabling more effective transition into policy and practice.^{2,3} For the changes to be sustainable more focus should be placed on developing dynamic capabilities. This enables context-

specific initiatives that can adapt to external changes so they can be utilized by other teams and organizations. Research teams can also produce more sustainable outcomes by developing partnerships with long-term funding as was done with the EmbrACE team and the Palix Foundation, so the changes do not stop after short-term funding is used up. 1

Building a diverse and unified team

An IKT team requires building partnerships with likeminded individuals through pre-existing relationships or development of new ones.²⁹ Building a multidisciplinary team allows for different points of view to come together to approach the development of a program/product in a more holistic way. For these collaborations to be successful the team must be unified in their goals and expectations. This requires regular communications and a respect for each person's expertise they bring to the table.⁵ The EmbrACE team engaged in monthly team meetings to maintain unity and empower research users by including knowledge users through every step of the process, not just during dissemination and implementation.¹

Extending the reach: Dissemination of findings

Research teams often focus on reporting their outcomes in terms of product knowledge but frequently fail to report procedural knowledge acquired. Sharing the procedural knowledge gained through reporting IKT strategies, the enablers and barriers, and secondary outcomes provides another stream of research they can create knowledge. The EmbrACE team reported details about how knowledge users were involved in the three phases of the study, allowing other teams to learn from them. They also used diverse dissemination strategies to share their findings through conferences, forums, luncheons, etc. that gave their findings more exposure but were more limited to an academic audience.

LEARNING GOALS

- 1. How IKT took shape to improve the likelihood that research findings generate more sustainable change for policy and practice.
- 2. How to seek out successful IKT partnerships with a diverse team and build team unity.
- 3. How to increase study impact through reporting and making the most of your multidisciplinary team.

ANALYSIS

IKT: Developing sustainable outcomes

Knowledge translation (KT) is an iterative process involving the synthesis and dissemination of knowledge. It also involves the exchange and application of knowledge to improve the health care system with more effective services and products. The KT field emerged to address an underuse of evidence-based research being implemented in practice with work to bridge the 'know-do' gap by connecting research to practice. However, KT projects are often done external to the environment so they can be impractical by requiring a revamp of current routines and the development completely new skills to implement. This makes it difficult to sustain when the study concludes. Instead, research teams should approach these initiatives with the local context in mind by considering the organizational routines and working to adapt/expand on existing skills, rather than requiring organizations to 'forget what they know.' Completely changing what an organization already does will not lead to a successful transition from research into practice or sustainable change. This is more likely to happen when the research team does not

have adequate knowledge about the local context. Therefore, to improve rates of success, research teams should consider having healthcare professionals involved in the project as agents of change rather than passive recipients of the changes.⁴

Integrated knowledge translation (IKT) involves developing relationships between researchers and knowledge users (e.g., decision makers, research funders, healthcare professionals, and the public) to conduct research that is beneficial for all parties involved and answering relevant research questions.^{2,3,13} This allows for the multi-disciplinary team to co-create knowledge that can be more effectively integrated into policy and practice. 5,14,15 The co-creation of knowledge encourages people to look beyond the idea of academic experts⁵ and to consider decision makers and knowledge users as experts in their respective areas. The IKT process aligns with the knowledge creation framework proposed by Graham, ¹¹ involving knowledge inquiry (primary research), synthesis of knowledge (reflects totality of evidence) and creation of knowledge tools. In addition to the more traditional engagement in this process, an IKT team is brought together by a common interest or research question. Next, the team must have the ability to articulate their knowledge so that their tacit experiential knowledge can be made explicit for sharing amongst the research team. Then the team's synthesized knowledge can be codified so it can be used to develop protocols, manuals, learning tools, decision support systems, etc. 16 With the synthesized knowledge from various areas of expertise used to form the local context, it allows for more effective engagement in Graham's 11 action cycle, makes the outcome more useful to the end user, and improves the likelihood that the initiatives can be implemented at an organizational level. 11,17,18

Another recommendation that could have strengthened the EmbrACE study or future IKT initiatives is to have a multi-jurisdictional team. For example, the SALTY research team investigating the complex and pressing challenges in long-term care homes consisted of four multidisciplinary teams across Canada.¹⁹ Having a multi-jurisdictional team makes the initiatives more sustainable by ensuring that the tools/procedures can adapt to different environmental factors. However, the long-term sustainability of an IKT initiative can be compromised if the organization doesn't have the resources to continue with the initiative after the short-term funding for the project is exhausted.^{20,21} This emphasizes the need to build the healthcare organization's internal capacity to apply, engage in, and utilize research. ^{4,22-26} Another way to combat this issue is to develop partnerships with foundations that can provide long-term funding as was done between the EmbrACE research team and the Palix Foundation. The Palix Foundation was involved in the proposal for the project and provided funding for all three phases. After completion of the three phases, a Palix staff member continued to be on the EmbrACE research team and show their support. This support also goes both ways, shown with the EmbrACE research team working alongside the Palix Foundation to organize a conference about the effects of ACEs in Calgary. Engaging in each others' initiatives can improve the sustainability of the partnership.²⁷ This demonstrates that with enough care and time given to developing an IKT partnership, it is more viable and more can be accomplished.^{3,28}

Building a diverse and unified team

When building an IKT team, there is an assumption the researchers are responsible for developing and maintaining IKT partnerships.⁵ Given this assumption, more literature addresses how researchers can initiate IKT partnerships with knowledge users (rather than the reverse). According to Zych et al,²⁹ 64% of researchers reported using pre-existing relationships to develop partnerships or get referrals. Some other

strategies reported included getting a linking agent to make the connections, conducting environmental scans, organizing KT workshops, and using a repository or shared forum to connect with likeminded individuals.^{29,30} CIHR³¹ recommends attending events or meetings in the community, visiting websites of potential partners, looking to prior working relationships, and getting involved in causes and issues important to the knowledge user. In the EmbrACE study, the Palix Foundation indirectly initiated the partnership by inviting members of the EmbrACE research team to a knowledge mobilization initiative they planned.¹ The event provided an opportunity to find people with a topic of mutual interest and/or have relevant experience, but this wouldn't have been the only contact between these teams before engaging in a partnership.³² Although this may not have been the case for the EmbrACE study, researchers have reported the need to convince knowledge users, over a series of communications, about how the product/service would benefit them in order to acquire the partnership.²⁹

With all the time and effort required to develop a partnership it is important to consider what attributes would be helpful given the context and environment for the study before seeking out these partnerships. ³¹ For example, when trying to generate tools or protocols for healthcare settings, healthcare professionals can provide information about the environmental enablers and barriers to implementation while the patient population can share their opinions and previous experiences to improve the tool or protocol. In the EmbrACE study, the patient group was able to influence the language used and steer the intervention protocol in a direction more favourable for that target audience. ¹ In addition to a primary care patient group, the EmbrACE research team included health researchers, psychologists, physicians, trainees, policymakers, and administrators. ¹ Building a multidisciplinary team shows an acknowledgment for the valuable insights each member can offer the team. This makes the knowledge users feel respected and valued; they become more committed to the project and build a greater sense of ownership, which leads to more successful IKT research. ^{29,33} This puts emphasis on the fact that building an IKT team does not just involve recruitment of likeminded people from multiple disciplines; it also involves unifying the team.

Developing a unified team requires group-level tacit knowledge that can be created though a series of social interactions.³⁴ This process starts before any research is conducted. With pre-existing partnerships, it can take anywhere from 6 months to 2 years.²⁹ When forming new partnerships, it can take up to 6 years.²⁸ During this time, the team needs to negotiate individual roles and contributions while also establishing clear leadership. ^{6,29,35} The team needs to discuss project timelines, policies, and generate project agreements to help manage expectations. ^{6,29,35} It is recommended that a plan is in place for collaborative negotiation/reassessment throughout the project as the team becomes more insightful about member skillsets and more informed about the time commitment and required effort so adjustments can be made if necessary. ^{6,35,36} This helps to manage expectations, build a shared language for effective communication, and enables the group to appreciate and understand each other's perspectives to generate a collective point of view. ⁵ Without this process it is more likely that members will commit less time to the project, feel less trust and respect for IKT partners, and feel a limited sense of belonging on the team. ^{6,34,37,38}

To build that sense of belonging, knowledge users should be involved throughout the project and not just during the dissemination and implementation of the findings.^{29,39} Their insights during grant applications, shaping the research question, methodological considerations, advising on tools for data collection (e.g., questionnaires), as well as the analysis and interpretation of results will strengthen the outcome.^{31,40-42} This

provides the opportunity for knowledge users to become more informed about the research process and helps to manage their expectations. Without a familiarity of research culture, knowledge users may experience positivity bias. This is when they assume that the collaborative research will result in actionable outcomes that can immediately impact policy and practice.^{3,5} However, it is likely that the research outcome is only a small piece to a much larger puzzle that needs to be completed before action can be taken.⁵ Putting in all that work and getting results that seem to have no impact because they are null or negative can be very discouraging and lead to a lack of enthusiasm for IKT research.⁵ Fortunately, IKT teams have two areas they can share knowledge: they have their primary products/interventions and they also have their IKT strategies.

Extending the reach: Dissemination of findings

To have a greater impact, IKT teams should report what was achieved in terms of their product knowledge, as well as *how* the study was conducted for their goals to be achieved.⁴³ Currently, there is minimal reporting of IKT strategies.⁶ More teams should share their IKT strategies for how they developed partnerships and how knowledge users were involved (i.e., degree of involvement, what phases of the project, etc.).^{6,44} Sharing a team's procedural knowledge, including what worked and what didn't, allows for larger scale impact of the findings. More extensive reporting also allows the team to share the other successes from the IKT process. Researchers develop a better understanding of healthcare practices and policy as well as the required skills to ask more applicable research questions, making their future research more useful.⁶ Knowledge users develop a better understanding of the research process and the required skills to use research more effectively. They become empowered to use more research in their practice, perceive research as more valuable, and become more willing to accept research findings, particularly when they are involved in the project.^{6,44-46} Reporting these strategies is invaluable for future research teams taking on IKT and necessary for growth of the IKT field.

IKT teams can also maximize the impact of their findings by using dissemination strategies just as diverse as their team. When thinking about what strategies to use, the IKT team should consider the objective, target audience, timeline, and resources required.²⁸ With a diverse team, you can more effectively address more target audiences and have more insight into the timeline and required resources needed for that target audience. The EmbrACE study used diverse dissemination strategies with a clinically validated tool, including publishing papers, organizing a conference with Palix, attending national and international conferences, using forums for ACE-related learning, and hosting luncheons.¹ With these strategies, patients benefit from improved care with the clinically validated tool, sharing their message with videos or live calls during the conference presentations, and getting to learn about the latest study findings at the luncheons organized for them and the stakeholders. However, these strategies are otherwise geared more towards academic audiences. Disseminating research to the public or patient population could be improved on by using social media platforms, press releases, websites, etc.^{47,48} This would have enabled the EmbrACE team to share their message with more people. More dissemination strategies and templates for composing dissemination documents can be found in The Knowledge Translation Toolkit book by Bennett and Jessani.⁴⁸

CONCLUSION

It is important to recognize that although presented as three distinct themes, the sustainability of IKT initiatives, the development of a multi-disciplinary team that is unified in their efforts and extending the reach of research findings cannot be separated. The success of each theme is dependent on the others. Developing more applicable and sustainable research is dependent on successful partnerships with a multidisciplinary team. The research becomes more applicable by drawing on the expertise of multiple disciplines to co-create knowledge so it can be more effectively integrated into policy and practice. 5,14,15 The research becomes more sustainable because group-level tacit knowledge of the local context can be used to frame initiatives around current practices to build the capacity for organizations to adapt to the changes without a complete revamp of practices. 4,22-26,34 For these things to happen, dissemination of the findings needs to occur to different groups of knowledge users, in addition to researchers. Having knowledge users as part of the team can help cater the message to each of the target audiences. The EmbrACE study experienced success largely due to the strong partnership with the Palix Foundation that provided funding and long-term support for their collective IKT initiatives. This partnership allowed for more diverse methods of dissemination with conferences, knowledge mobilization sessions, forums, etc. and more sustainable research by fitting the research into the local context with the help of knowledge users. In this case, the extensive involvement of the primary care patient group had a substantial role in making this possible.

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