

how we work together

THE INTEGRATED KNOWLEDGE TRANSLATION RESEARCH NETWORK CASEBOOK

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EDITED BY LAURA BOLAND, JESSICA RESZEL, CHRIS MCCUTCHEON, ANITA KOTHARI & IAN D GRAHAM



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FOREWORD

Christine Cassidy

Integrated knowledge translation (IKT) is a collaborative research approach focused on “doing research with the people who use it” to increase the relevance and use of research findings in health practice, programs and policies.^{1,2} Despite its benefits, collaborative research is not easy; studies report many challenges with developing and maintaining meaningful research partnerships.^{3,4} Effectiveness in collaborative health services research, including IKT, requires researchers to have specific knowledge and skills for working in partnership with health system decision makers.⁵ Previous research from the Integrated Knowledge Translation Research Network (IKTRN) explored Canadian health system leaders’ perspectives on research collaborations and found that researchers often lack an understanding of how to work collaboratively within the health system context. Participants identified the need to improve academic preparation for engaging in health services research partnerships.⁶

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There is no roadmap or user manual for research trainees to work collaboratively with the health system; nor will you find a how-to guide in your university’s graduate studies handbook.

Most graduate students do not receive formal training in collaborative health services research.^{7,8} There is no roadmap or user manual for research trainees to work collaboratively with the health system; nor will you find a how-to guide in your university’s graduate studies handbook. Graduate students and post-doctoral trainees who engage in collaborative research are often self-motivated to do so and supported by their supervisors to participate in experiential learning opportunities.⁹ I was first introduced to IKT through an informal learning opportunity during my doctoral studies. My PhD supervisor connected me with a group of clinicians and administrators at our local children’s health centre to support them in implementing evidence-based practices into care. Before I knew it, we were applying an IKT approach to our research projects; as a research trainee, I was “doing

research with the people who use it.” I wrote about this partnership in Volume 1 of the IKTRN casebook and subsequently received the Collaborative Healthcare Improvement Partnerships (CHIPS) Student Award.¹⁰ Since writing about our IKT experience in 2016, our research partnership has continued to grow. We now work collaboratively on a program of research aimed at using an IKT approach to design, implement and evaluate evidence-based practices in pediatric care.^{11,12} Our health system partners identify the research questions and contribute their clinical expertise, while our academic partners apply their research skills to address relevant practice issues.

Although I learned about IKT through trial and error, I wish I had clear guidance on how to be an effective research partner from the start of my graduate studies. This third volume of the IKTRN casebook begins to codify trainees’ tacit knowledge on how to work in collaboration with the health system. Based on their personal experience in using an IKT approach to research, six trainees offer many “golden nuggets” of information for other trainees interested or involved in collaborative research.

As described in the six cases to follow, trainees applied an IKT approach across a variety of health-care settings, including acute care, public health and an international non-governmental organization. Many

trainees stumbled upon IKT through an introduction from their supervisors, or unintentionally applied IKT principles (e.g., developed relationships with health system partners), before learning the details behind this approach to collaborative research. These trainees engaged a range of knowledge users (defined as an individual likely to use research results in their practice of decision-making¹³), including health-care providers, senior-level leadership in health-care organizations and advisory committees to contribute throughout the research process – from project inception through to knowledge dissemination.

As you will read, this casebook illustrates the positive impact of an IKT approach on the research process, study findings and the trainee experience. First, for many trainees, the IKT partnerships with knowledge users facilitated the research process. Knowledge users contributed a valuable understanding of organizational policies and procedures and facilitated buy-in from key members of the organization. Second, trainees believed that the IKT approach added richness and relevance to their research findings and helped support the project's acceptability within organizations. Third, by cultivating meaningful partnerships throughout the research process, the IKT approach supported the sustainability of changes in the health-care system. This level of engagement facilitated mutual learning for the trainee and knowledge-user partners and was described as a worthwhile and rewarding experience for research trainees.

Despite these benefits, using an IKT approach in research can be challenging for trainees. The cases to follow offer valuable lessons on common challenges and strategies to overcome them. For example, health system partners have many competing priorities. The trainees had to find a balance of communication to keep people informed and engaged in the process, without overloading them with information. Further, several trainees described a high level of turnover in their organization; there were challenges with continued engagement and having to restart partnership development with new staff members. Given these challenges, all six cases described the need to be adaptable and flexible to address key health system issues and maintain relevance of the research. The ability to be adaptable and flexible was easier when there were pre-existing, well-established relationships. As mentioned in several cases, considerable time and effort is needed to develop meaningful partnerships and encourage efficient collaborative research.

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Building on their experience of learning by doing, these trainees offer several recommendations for other students and post-doctoral fellows interested or involved in collaborative health research. Across the board, trainees highlighted the importance of partnership development and maintenance. It is important to invest time to plan, communicate, listen and work together. Trainees recommend a flexible and adaptable approach to support health system partners and adapt as needed based on their context. Questions remain on how to find the right balance between adaptability and research rigour. What research designs support this adaptable approach to health services research? Further, many of the trainees encourage others to monitor and evaluate their IKT approach to contribute to the growing literature on the science of IKT. This will be critical as we advance the field of IKT to generate more relevant and useful research findings. Lastly, they encourage other trainees to enjoy this enriching process of mutual learning and exchange with health system partners.

Throughout this casebook, you will read about the feasibility and importance of using an IKT approach in health services research. In an attempt to codify the tacit knowledge of trainees involved in IKT research, these cases highlight their lessons learned on how to engage in research partnerships while also learning how to do applied health services research. These cases set the stage for how we can build on these lessons learned to better support trainees to work in collaboration with the health system. Efforts are needed to formalize graduate training in IKT to reap its benefits on trainees, the research process and the health system. While there is still work to do, if the cases to follow are any indication, the future of IKT is in good hands.

Christine Cassidy RN PhD

Assistant Professor, School of Nursing
Faculty of Health, Dalhousie University
Affiliate Scientist, IWK Health Centre

References

1. Integrated Knowledge Translation Research Network. 2020. Available from: <https://iktrn.ohri.ca/>
2. Kothari A, McCutcheon C, Graham ID. Defining integrated knowledge translation and moving forward: a response to recent commentaries. *Int J Health Policy Manag.* 2017;6(5):299-300.
3. Gagliardi AR, Berta W, Kothari A, Boyko J, Urquhart R. Integrated knowledge translation (IKT) in health care: a scoping review. *Implement Sci.* 2016;11:38.
4. Oliver K, Kothari A, Mays N. The dark side of coproduction: do the costs outweigh the benefits for health research? *Health Res Policy Syst.* 2019;17(1):33.
5. Barratt H, Shaw J, Simpson L, Bhatia S, Fulop N. Health services research: building capacity to meet the needs of the health care system. *J Health Serv Res Policy.* 2017;22(4):243-249.
6. Bowen S, Botting I, Graham ID, MacLeod M, de Moissac D, Harlos K, et al. Experience of health leadership in partnering with university-based researchers in Canada – a call to “re-imagine” research. *Int J Health Policy Manag.* 2019;8(12):684-699.
7. Bornstein S, Heritage M, Chudak A, Tamblyn R, McMahon M, Brown AD. Development of enriched core competencies for health services and policy research. *Health Serv Res.* 2018;53(S2):4004-4023.
8. McMahon M, Bornstein S, Brown A, Tamblyn R. Training for impact: PhD modernization as a key resource for learning health systems. *Healthc Policy.* 2019;15(SP):10-15.
9. Cassidy CE, Bowen S, Fontaine G, Côté-Boileau É, Botting I. How to work collaboratively within the health system: workshop summary and facilitator reflection. *Int J Health Policy Manag.* 2019;9(6):233-239.
10. Cassidy C, Foley L, Rowe ME, Best S, Curran J. Fostering an academic-clinical partnership to redesign care on a pediatric inpatient unit. In: McCutcheon C, Kothari A, Graham I, eds. *How We Work Together: The Integrated Knowledge Translation Casebook*. Volume 1. Ottawa, ON: Integrated Knowledge Translation Research Network;2019. p 29-30. Available from: <https://iktrn.ohri.ca/projects/casebook/>
11. Cassidy C, MacEachern L, Egar J, Best S, Foley L, Rowe ME, et al. Barriers and enablers to implementing a high-dependency care model in pediatric care. *J Nurs Care Qual.* 2019;34(4):370-375.
12. Cassidy CE, MacEachern L, Best S, Foley L, Rowe ME, Dugas K, et al. Barriers and enablers to implementing the Children’s Hospital Early Warning Score: A pre- and post-implementation qualitative descriptive study. *J Pediatr Nurs.* 2019;46:39-47.
13. Canadian Institutes of Health Research. Knowledge User Engagement. 2012. Available from: <https://cihr-irsc.gc.ca/e/49505.html>

Working with hospital teams to treat food as medicine

Celia Laur^{1,2}, Donna Butterworth³, Roseann Nasser⁴, Marilee Stickles-White⁵,
Mei Tom⁶, Heather Keller²

¹Women's College Hospital; ²University of Waterloo; ³Concordia Hospital; ⁴Pasqua Hospital; ⁵Niagara Health System; ⁶Alberta Health Services

INTRODUCTION

Trainee background

As an implementation scientist, I continue to learn about integrated knowledge translation (IKT) from the experts including other researchers, health-care professionals, health system stakeholders and individuals with lived experience. I had been unwittingly applying IKT principles, including involving relevant individuals from the health system and building relationships with all involved, for several years before I started to learn the details. I am particularly interested in how IKT can support effective interventions to be sustained and spread. This interest started during my PhD research at the University of Waterloo, with the More-2-Eat (M2E) implementation projects to improve nutrition care in Canadian hospitals (Phase 1)¹ and sustain and spread the impact (Phase 2). These projects provide great examples of IKT in action, cultivating a hospital culture that food is medicine.

Project

Forty-five per cent of people who stay two or more days in Canadian hospitals are malnourished, and two-thirds of these individuals leave hospital still malnourished.² Malnutrition has been shown to independently increase mortality, length of stay and risk of readmission – all of which affect patient flow and, ultimately, health-care costs.^{2–4} In M2E Phase 1 (2015–2017) we collaborated with five hospitals across Canada to improve nutrition care by incorporating best-practice strategies

such as nutrition screening at admission and a standardized assessment for those screened at risk of malnutrition. To provide some direction, suggested strategies were based on the literature and expert consensus from a previous project,^{1,2} and each hospital decided which respective strategies were most relevant. This approach resulted in dietitian-directed patient nutrition care that was more timely and more appropriate.^{5,6} In Phase 2 (2018–2019), four of the original hospitals spread the successful changes they had made in the original units to new units, while six new hospitals started implementation. This time, we wanted to understand if and how this approach to improving nutrition care could be sustained and spread with minimal researcher input or additional funding.

Knowledge users

In Phase 1 and 2, the research team worked with local champions who were, in most cases, already employed as dietitians within managerial or leadership roles. Since the project was focused on nutrition care, many hospitals felt these dietitians were key champions who could recruit other key health-care team members. As such, each hospital selected at least one prospective champion prior to their application to be part of the research team. While the clinical expertise of these dietitians was an asset in terms of ensuring appropriate hospital and regional procedures were followed, most were new to the implementation of large initiatives such as M2E.

Each dietitian champion led an interdisciplinary “Site Implementation Team” of hospital staff who could plan and implement the changes within their respective hospitals. The M2E champion and site leadership assembled teams based on local availability, hospital recognition of who could influence change in specific areas and expressions of interest in being involved. They typically selected nursing and foodservice management as key members. Teams were fluid in that members fluctuated according to the interventions being implemented; for this reason, they sometimes included direct care staff. Moreover, certain team members led specific initiatives. For example, a nurse lead supported the implementation of nutrition screening, whereas a volunteer coordinator facilitated volunteer involvement during mealtimes. The research team mainly communicated with the dietitian champion, who would relay relevant information to the site team. M2E Research Associates were also involved to collect data and supported implementation. These Associates were selected at the beginning of the project based on role, capacity, experience and interest.

From the beginning, we worked closely with the Canadian Malnutrition Task Force (CMTF)⁷ with the aim that they would provide the foundation needed by hospitals to sustain this work. At the time, Professor Heather Keller was chair of the CMTF and the intention was that after the research project was complete, the CMTF would continue to support the champions and hospitals as needed. The online toolkit, which was created based on the results, was hosted on the CMTF website.⁸

DESCRIPTION OF THE IKT EXPERIENCE

Setting up the project

In Phase 1, hospitals applied to be part of M2E before funding was obtained in order to demonstrate their interest in participating. The research team trained champions from the five selected hospitals on behaviour change, change

management and the Integrated Nutrition Pathway for Acute Care (INPAC).^{6,9} The champions and their teams decided which aspects of INPAC made sense to implement in their hospital and how to make those changes. Researchers, including one faculty member, one PhD student, one post-doctoral researcher and one master's student supported the hospitals through training, monthly group calls with champions, monthly analysis of INPAC audit data,^{1,10} interviews with staff and management^{11,12} and analysis of a staff survey.^{13,14} All results, particularly INPAC audits, were reported back monthly to the champions, who then shared them with their site teams to inform implementation.

Becoming partners

By the time we were applying for funding for Phase 2, the champions had truly become partners in this work, including contributing to discussions on what Phase 2 should look like, the priority areas of INPAC implementation, the identification of key strategies and sustainability. The champions also helped to design data collection methods and auditing tools, while providing additional input for the online toolkit being developed based on Phase 1 results.⁸ The Phase 1 champions became mentors for Phase 2 hospitals, providing real-life experience with implementation and ways to effectively improve care practices. This connection was initiated through monthly calls and continued outside of the calls. Champions were also having a national impact through media appearances, providing support to hospitals outside of the project, presenting at research and professional conferences and co-authoring several publications. Many of the dietitians involved were also seeing their own role differently. In the words of one of them:

“Dietitians need to advocate for themselves... We need to show that we're actually making change, and helping patients, and keeping them out of hospital, and putting safety nets in place in the community. That's our job. I don't think that up to

this point that I really realized that we could do all those things."

Researchers leading the project provided the structure and support to hospital champions. We tried to make it a little easier, but it was really the passion and drive of the champions and their teams that made this work possible. Champions and teams adapted M2E models to do what was needed for their hospital, using approaches adapted for their context. For example, one hospital was undergoing a period of significant change to service delivery. When M2E implementation was not operationally possible on the nursing units, the team deferred unit changes and focused on processes that were led by and accountable to nutrition and food services. The flexibility provided within this approach allowed each hospital the time needed to engage the right people and implement changes in a way that could be sustained within their hospital.

Common challenges included competing priorities, treatment of the work as a "project" rather than focusing on sustained change, finding a communication balance that kept people informed yet not overloaded, funding to support champion time after the study ended, and continual changes to the site implementation teams due to variable capacity and staff turnover. The monthly meetings with other sites provided ideas on how to overcome these challenges.

Sustained success was facilitated by building change into policy and embedding it into normal practice, upper management support, alignment of changes with hospital priorities, and dissemination of research findings showing the impact on practice changes and length of stay. In supporting five hospitals in Phase 1, and 10 in Phase 2, it was challenging for the researchers to keep track of all aspects of the changes that were

being made. However, this "hands-off" approach, particularly for Phase 2, allowed hospitals to "own" the changes they were making and find ways to continue this work after funding ended. This collaborative combination of research and practice showed that although change is difficult and takes time, it is possible.

What I would do differently

Although we followed the Knowledge to Action Framework,¹⁵ if I were to do anything differently, I would have tried to learn more about IKT before starting the project so we could have used more IKT tools and frameworks. I would have conducted an evaluation of how the champions felt about their involvement in the research process, along with their role in changing hospital practice. I would have also had more input from individuals with lived experience as a hospital patient, encouraging each hospital to include them on their Site Implementation Team.

Keeping it going

We all tried to think of sustainability from the beginning by involving local champions and having them set their own priorities. This use of an IKT approach helped to support the sustainability of the changes. Those involved in the work agreed that M2E was more than a research study, and many of the behaviours, such as screening and food intake monitoring, were built into the daily work of the staff in order to sustain the change. As described by one hospital team member:

"...I think this [M2E] is just a start, and after the study is over we need to continue and that is something that speaks to me loud and clear, that this isn't just something that stops after the study is over. We've got to keep going and figuring out how we can continue making it important, and that nutrition is important and that food is medicine."
(M2E Dietitian/Research Associate)

CONCLUSIONS

The extent of our local and national impact was possible with the use of this participatory approach. Local expertise in each hospital drove the implementation and resulted in sustained impact and spread to other hospital units. The CMTF continues to make hospital malnutrition a priority across Canada and supports hospitals to sustain their changes and spread to new locations. The combined effort of local experts and researchers embedded in a national organization, CMTF, supported the national profile and legitimacy of the work, which has already made a national impact on nutrition care in Canada. The CMTF is working toward sustaining this impact.

THREE RECOMMENDATIONS FOR TRAINEES

- 1 Ask questions and listen to the answers. There is so much you can learn from your partners and so much they can learn from you too.
- 2 Be flexible. Trust that your partners understand their setting and let them lead. Provide the best support you can and adapt as needed.
- 3 Be kind. At the end of the day, we are all here to help and support each other while stretched for time and resources. Kindness goes a long way.

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REFERENCES

1. Keller H, Laur C, Valaitis R, Bell J, McNicholl T, Ray S, et al. More-2-Eat: evaluation protocol of a multi-site implementation of the Integrated Nutrition Pathway for Acute Care. *BMC Nutr.* 2017;3:13.
2. Allard J, Keller H, Jeejeebhoy K, Laporte M, Duerksen D, Gramlich L, et al. Malnutrition at hospital admission: contributors and effect on length of stay: a prospective cohort study from the Canadian Malnutrition Task Force. *J Parenter Enteral Nutr.* 2016;40(4):487–497.
3. Curtis L, Bernier P, Jeejeebhoy K, Allard J, Duerksen D, Gramlich L, et al. Costs of hospital malnutrition. *Clin Nutr.* 2017;36(5):1391–1396.
4. Ramage-Morin P, Gilmour H, Rotermann M. Nutritional risk, hospitalization and mortality among community-dwelling Canadians aged 65 or older. *Health Rep.* 2017;28(9):17–27.
5. Keller H, Valaitis R, Laur C, McNicholl T, Xu Y, Dubin J, et al. Multi-site implementation of nutrition screening and diagnosis in medical care units: success of the More-2-Eat project. *Clin Nutr.* 2019;38(2):897–905.
6. Keller H, McCullough J, Davidson B, Vesnaver E, Laporte M, Gramlich L, et al. The Integrated Nutrition Pathway for Acute Care (INPAC): building consensus with a modified Delphi. *Nutr J.* 2015;14:63.
7. Canadian Malnutrition Task Force. 2019. Available from: <https://nutritioncareincanada.ca/>
8. Canadian Malnutrition Task Force. INPAC implementation toolkit. 2018. Available from: m2e.nutritioncareincanada.ca/
9. Keller H, Laur C, Atkins M, Bernier P, Butterworth D, Davidson B, et al. Update on the Integrated Nutrition Pathway for Acute Care (INPAC): post implementation tailoring and toolkit to support practice improvements. *Nutr J.* 2018;17(1):2.
10. Valaitis R, Laur C, Keller H, Butterworth D, Hotson B. Need for the Integrated Nutrition Pathway for Acute Care (INPAC): gaps in current nutrition care in five Canadian hospitals. *BMC Nutr.* 2017;3:60.
11. Laur C, Valaitis R, Bell J, Keller H. Changing nutrition care practices in hospital: a thematic analysis of hospital staff perspectives. *BMC Health Serv Res.* 2017;17(1):498.
12. Laur C, Bell J, Valaitis R, Ray S, Keller H. The Sustain and Spread Framework: strategies for

sustaining and spreading nutrition care improvements in acute care based on thematic analysis from the More-2-Eat study. *BMC Health Serv Res.* 2018;18(1):930.

13. Laur C, Keller H, Curtis L, Douglas P, Murphy J, Ray S. Comparing hospital staff nutrition knowledge, attitudes, and practices before and 1 year after improving nutrition care: results from the More-2-Eat implementation project. *J Parenter Enteral Nutr.* 2018;42(4):486–796.

14. Laur C, Marcus H, Ray S, Keller H. Quality nutrition care: measuring hospital staff's knowledge, attitudes, and practices. *Healthcare.* 2016;4(4):E79.
15. Graham ID, Logan J, Harrison MB, Straus SE, Tetroe J, Caswell W, et al. Lost in knowledge translation: time for a map? *J Contin Educ Health Prof.* 2006;26(1):13–24.

ABOUT THE AUTHOR



DR. CELIA LAUR is an implementation scientist and health services researcher who works across disciplines and settings to understand how effective interventions can be sustained, spread and scaled-up. Her PhD at the University of Waterloo in the School of Public Health and Health Systems, supervised by Prof Heather Keller, used an integrated knowledge translation approach to understand health-care professionals' perspectives on implementing, sustaining and spreading nutrition care activities in hospitals across Canada. Her PhD was funded by the CIHR Doctoral award and also through an Interdisciplinary Fellowship with the Canadian Frailty Network. She is currently a CIHR Health System Impact Fellow (post-doctoral), based at Women's College Hospital and the University of Toronto. Her current supervisors are Dr. Noah Ivers and Dr. Sacha Bhatia. Dr. Laur is also Associate Director of the UK NNEdPro Global Centre for Nutrition and Health.

A doctoral student perspective about using integrated knowledge translation to evaluate a pediatric shared decision-making program

Laura Boland^{1,2}

¹Western University; ²Ottawa Hospital Research Institute

INTRODUCTION

My initial exposure to integrated knowledge translation (IKT) occurred serendipitously, with a series of events that gave rise to using an IKT approach for my doctoral studies in population health at the University of Ottawa in Canada. Prior to my doctoral studies, I was the research coordinator for a program that aimed to implement shared decision-making at the Children's Hospital of Eastern Ontario (CHEO). My position allowed me to work with knowledge users (i.e., parents, children, health-care providers and senior hospital administration) who could use the research to inform practice and policy,¹ laying the foundations for using an IKT approach for my doctoral studies. In these early stages of my research, it became apparent that partnering with knowledge users would improve the quality and knowledge transfer of my research findings.

Shared decision-making involves the participation of the health-care team, parents and children in reaching a decision via collaborative partnership, with a common goal for the child's health.^{2,3} High-quality evidence underpins the tools and strategies that promote shared decision-making.^{4,5} However, the benefits of shared decision-making have not been extended to pediatric populations and little is known about the factors that influence the implementation of shared decision-making in pediatric clinical practice.^{6,7} The overarching purpose of my dissertation, which is now complete, was to evaluate factors that influence the

implementation of shared decision-making in pediatric clinical practice.

My introduction to IKT came from my supervisor, Dr. Dawn Stacey, and thesis committee member, Dr. Ian D Graham, who encouraged me to partner with knowledge users to improve the relevance and impact of my research. Therefore, during study conceptualization, I asked a clinician-scientist with whom I had a previous working relationship at CHEO to be a committee member and represent a knowledge-user perspective on my thesis. I thought this individual would be an ideal knowledge user because she had expertise in pediatric shared decision-making, was the medical director of the CHEO shared decision-making program, was a respected pediatric endocrinologist at CHEO and had a clinician-scientist background. During the data collection stages of my dissertation research, CHEO hired a registered nurse with expertise in shared decision-making to be the research coordinator for the shared decision-making program. As such, I invited her to become an additional knowledge user on my doctoral research project. Given the parallels between my shared decision-making research and her coordinator and clinical nursing roles, we found it natural to establish a strong and mutually beneficial research partnership based on our unique perspectives.

DESCRIPTION OF THE IKT EXPERIENCE

The knowledge-user and researcher partnership was the result of a natural progression founded on

positive previous working relationships and the shared common goal to close the shared decision-making evidence-practice gap at CHEO. As a doctoral student, my role was to lead the dissertation research while my supervisor, along with my thesis committee members and the knowledge users, guided the process. Although I did not follow specific theoretical frameworks or guidelines for conducting the IKT approach, several of my thesis committee members were IKT experts and provided invaluable guidance for implementing successful IKT strategies.

I did not base my communication with knowledge users on a plan or framework, but rather on my knowledge of interdisciplinary team science and the needs of the research team and project. As a first step, I held an early meeting to introduce the research team, comprising myself, my supervisor and my thesis committee, including the knowledge users. We discussed my research direction and made explicit each other's roles and expected contributions. We had regular team meetings (i.e., three to four times per year as per consensus of the team) and I sent regular progress updates to all research team members to maintain contact between meetings. The research team was involved in all stages of the research process, from study conceptualization to the dissemination of findings. All researchers and knowledge users contributed to the intellectual content, data collection, analysis and interpretation, and they were authors on all relevant presentations and publications.

Lessons learned

I learned several, mainly positive, lessons from using an IKT approach for my doctoral research. First, I believe that working with knowledge users significantly facilitated my research. For example, the knowledge users provided invaluable insights, such as factors to consider within CHEO's research culture, senior staff to talk to and how to overcome barriers to conducting research at CHEO. Additionally, these knowledge users

facilitated organizational and provider buy-in of my research. For example, through my knowledge users, senior-level administrators became aware of and endorsed my research because it addressed questions pertinent to shared decision-making at CHEO. The knowledge users also understood the inner workings of their organization, which allowed us to tailor the research approach to facilitate progress and data collection. For example, we had the "inside information" (e.g., dates and times of rounds, busy clinic days, slowdown periods) needed to maximize attendance at the shared decision-making educational workshops. Moreover, knowledge-user input regarding interview-guide and survey development, recruitment and data collection methods made the data more relevant to those who would use the findings. Finally, I was able to recruit study participants with ease (e.g., achieved an 88 per cent health-care provider response rate) because health-care providers worked with and respected the knowledge users, thereby providing credibility to the research.

I experienced numerous facilitators and few challenges in using an IKT approach for my doctoral research. Contrary to popular belief that IKT takes more time, I believe that IKT expedited completion of my doctoral research. The knowledge users were in an ideal position to anticipate and overcome barriers and could advise me on how to tailor my research to organizational processes and clinical workflow. The knowledge users also had shared decision-making research experience, which meant that building their capacity for partnering in research and in shared decision-making content was not necessary or appropriate. This allowed our research team to speak a common language from the beginning.

Despite the overall success of the research, in hindsight I might have done a few things differently. First, I think the research would have been enhanced with representation from pediatric patients and parents. Although including a child

and parent as part of the research the team might have presented challenges (e.g., additional time, capacity building, deadline expectations), the returns would have been worth the investment, particularly as shared decision-making is an intervention designed to improve outcomes for patients and families. Second, I think it would have been beneficial to have capitalized on the knowledge users' expertise and explicitly and iteratively planned for post-study implementation of the shared decision-making program.⁸ In the post-doctoral phases of my shared decision-making research, I will be including post-study implementation planning with knowledge users from the early phases of the project. Finally, given that the science of IKT is still emerging, I would have prospectively planned and conducted a study to evaluate outcomes related to using IKT approaches during my training.

CONCLUSIONS

In conclusion, using an IKT approach facilitated the successful and timely completion of my doctoral research while also enhancing its relevance. The research outputs (e.g., recommendations) were specific to the organization, thus increasing their potential for implementation and impact post-study. At the same time, these outputs were generalizable to other pediatric centers.

Given my positive experiences with using IKT approaches, I would advise that other trainees consider early and ongoing partnership with knowledge users throughout their doctoral research and academic careers. Using an IKT approach is likely to enhance the credibility of the trainee's research and facilitate buy-in from other stakeholders, both organizations and individuals. Moreover, since trainees need to graduate and conduct their research within a reasonable timeframe, I would suggest that, where possible, trainees partner with knowledge users who have research and content knowledge. Doing so could help to streamline the research process while

minimizing other potential barriers. Finally, I would encourage trainees to monitor and evaluate the IKT approaches used during their training to add to the state of the science in IKT. In sum, I found using an IKT approach added richness, relevance and efficiency to my doctoral experience and research. I will continue to use IKT approaches throughout my research career.

THREE RECOMMENDATIONS FOR TRAINEES

1

Consider early and ongoing partnership with knowledge users to enhance the credibility of the research and facilitate buy-in from other stakeholders.

2

Where possible, partner with knowledge users who have research and content knowledge to streamline the research process and minimize barriers.

3

Monitor and evaluate the IKT approaches used during training to add to the state of the science in IKT.

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REFERENCES

1. Kothari A, Wathen C. A critical second look at integrated knowledge translation. *Health Policy*. 2013;109(2):187-191.
2. Park ES, Cho YI. Shared decision-making in the paediatric field: a literature review and concept analysis. *Scand J Caring Sci*. 2018;32(2):478-489.

3. Légaré F, Stacey D, Pouliot S, Gauvin FP, Desroches S, Kryworuchko J, et al. Interprofessionalism and shared decision-making in primary care: a stepwise approach towards a new model. *J Interprof Care*. 2011;25(1):18-25.
4. Stacey D, Légaré F, Lewis K, Barry MJ, Bennett CL, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2017;4:CD001431.
5. Stacey D, Kryworuchko J, Bennett C, Murray MA, Mullan S, Légaré F. Decision coaching to prepare patients for making health decisions: a systematic review of decision coaching in trials of patient decision AIDS. *Med Decis Making*. 2012;32(3):E22-33.
6. Fiks AG, Jimenez ME. The promise of shared decision-making in paediatrics. *Acta Paediatr*. 2010;99(10):1464-1466.
7. Feenstra B, Boland L, Lawson M, Harrison D, Kryworuchko J, Leblanc M, et al. Interventions to support children's engagement in health-related decisions: a systematic review. *BMC Pediatr*. 2014;14:109.
8. Stacey D, Suwalska V, Boland L, Lewis K, Presseau J, Thomson R. Are patient decision aids used in clinical practice after rigorous evaluation? A survey of trial authors. *Med Decis Making*. 2019;39(7):805-815.

ABOUT THE AUTHOR



DR. LAURA BOLAND is post-doctoral fellow co-located at Western University and the Ottawa Hospital Research Institute (CIHR funded, 2018-2022). Her supervisors are Drs. Anita Kothari and Ian Graham. She holds a PhD in Population Health from the University of Ottawa (2018; supervisor Dr. Dawn Stacey) and a MSc in Speech Language Pathology from Dalhousie University (2008). Dr. Boland's research program aims to improve health service and patient outcomes by using knowledge translation approaches to promote shared decision-making (i.e., patient, family, and health-care team partnership in making health decisions). She sits on the Integrated Knowledge Translation Research Network (IKTRN) Executive Committee (Trainee Capacity Building Portfolio), and is a member of the International Patient Decision Aid Standards Collaboration, the Patient Decision Aid Research Group and the Centre for Implementation Research.

An integrated knowledge translation approach to co-design a complex exercise intervention for stroke survivors: A case report

Emily R Ramage¹⁻⁴, Meredith Burke¹, Margaret Galloway¹⁻⁴, Heidi Janssen¹⁻⁵,
Elizabeth A Lynch^{3,6}, Dianne L Marsden¹⁻⁴, Amanda J Patterson^{1,4,7},
Catherine M Said⁸⁻¹⁰, Coralie English¹⁻⁴

¹University of Newcastle; ²Priority Research Centre for Stroke and Brain Injury; ³Centre of Research Excellence in Stroke Rehabilitation and Brain Recovery; ⁴Hunter Medical Research Institute; ⁵Hunter New England Local Health District; ⁶University of Adelaide; ⁷Priority Research Centre for Physical Activity and Nutrition; ⁸University of Melbourne; ⁹Western Health; ¹⁰Australian Institute of Musculoskeletal Science

INTRODUCTION

I am a physiotherapist and PhD candidate in physiotherapy at the University of Newcastle, Australia. I came across the integrated knowledge translation (IKT) approach when seeking a method to guide an intervention co-design process, and I had no previous experience in the area.

Project

People living with stroke often have low levels of physical activity,^{1,2} which increases their risk of having another stroke.^{3,4} Evidence supports the use of supervised exercise to reduce the risk of stroke recurrence.^{5,6} Interventions delivered via telehealth have the potential to overcome common barriers such as distance and transport^{7,8} to exercise after stroke. My doctorate study involves the co-design and piloting of an evidence-based intervention aimed at increasing physical activity to reduce secondary stroke risk. This case describes the co-design of this intervention, which applied an IKT approach using a pre-defined framework (Figure 1). Our approach aligned with recommendations from the Stroke Recovery and Rehabilitation Roundtable⁹ and the Medical Research Council's framework for complex intervention development and evaluation.¹⁰

Knowledge users

Our research team consisted of knowledge-user partners and researchers (myself and my PhD supervisors), involved throughout all stages of the project (Figure 1). The researchers conceived the project and determined which knowledge-user groups needed to be represented on the team. Individuals representing these groups were identified through the professional networks of my supervisors.

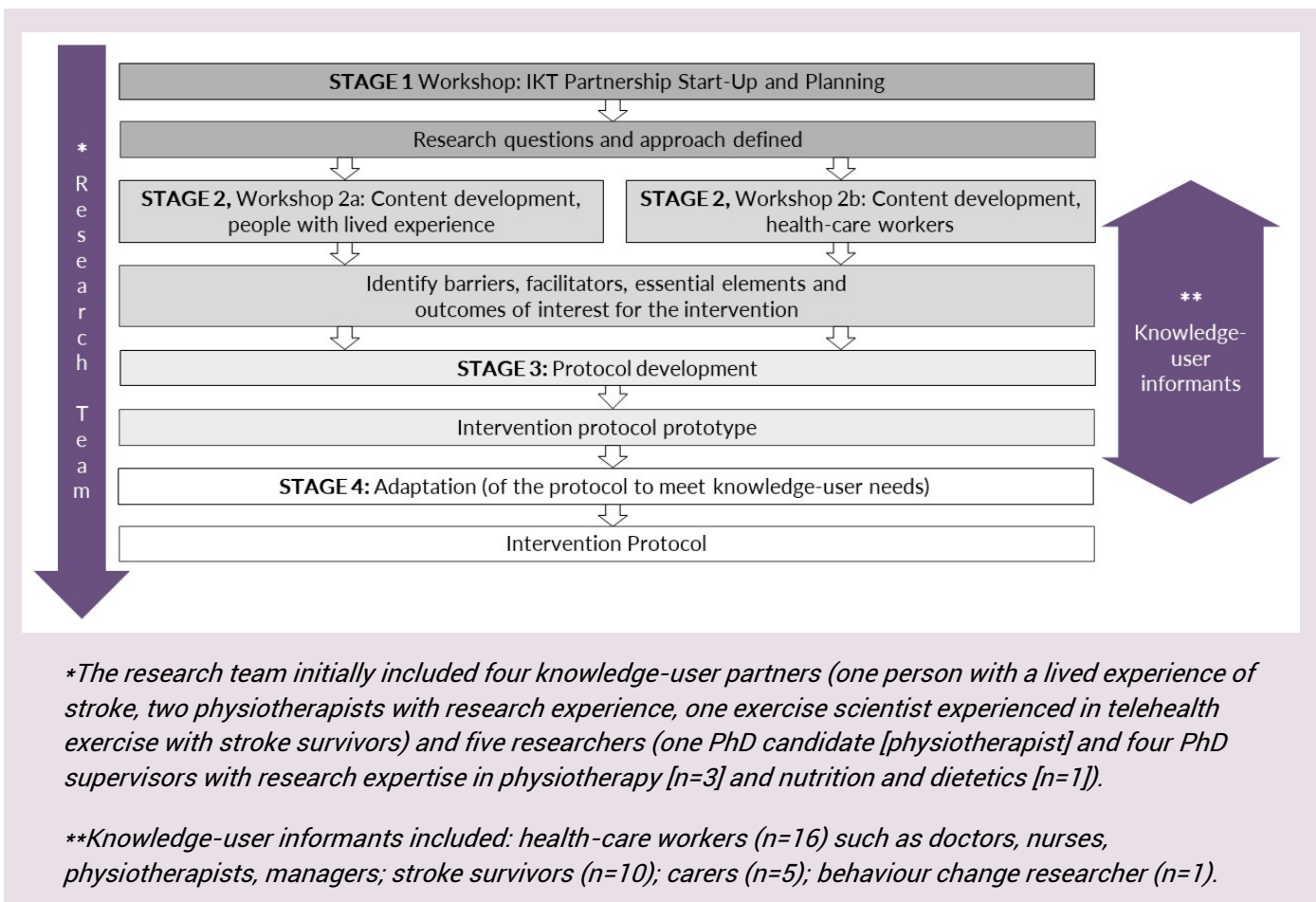
A seven-month timeframe and lack of funding limited engagement of further knowledge users on the research team. To provide a more diverse range of knowledge-user experiences and opinions to inform the intervention, 32 additional knowledge-user informants were engaged in the project (Figure 1), and an additional clinician joined the research team following the start-up and planning workshop.

DESCRIPTION OF THE IKT EXPERIENCE

Establishing and facilitating the IKT partnership

My principal PhD supervisor had worked previously with all members of the research team and invited all knowledge-user partners to join in the few months leading to the start-up and

Figure 1. Framework for the application of the IKT co-design



planning workshop. The IKT partnership was established primarily at this first face-to-face workshop (which included one member who was teleconferencing from interstate). At this workshop, the research questions, structure and intended outcomes of the project were largely decided. Feedback from the workshop attendees on the processes and outcomes of all workshops was encouraged (via email, phone or in-person), resulting in the evolution of some decisions over the life of the project (e.g., communication strategies used, workshop content and knowledge-user participation).

Strategies used to support the IKT partnership included:

- Verbal reinforcement of the IKT principles within the research team of shared decision-making and partnership¹¹ and working in an environment of mutual respect.¹²
- The use of clear and common language.¹³ After a lack of effective communication was identified as negatively impacting participation in the start-up and planning workshop, we worked reactively to implement strategies including more lay language and supported conversation techniques to support our partner with a lived experience of stroke and aphasia.
- Maximizing in-person attendance at project workshops.
- Summaries from all of the workshops (Stages 1-4) were sent to their contributors, with opportunity provided for amendment.

Roles and contributions of the project team

In lieu of formal training or previous experience in IKT, I reviewed the literature about IKT research to develop my understanding of the IKT philosophy and its applications. My role on the project team was to co-ordinate the project and facilitate all workshops. Two researchers on the team were also my PhD supervisors who co-facilitated some of the larger workshops. All of my PhD supervisors provided support throughout the project (e.g., advice and support regarding progression of the project, workshop facilitation and workshop summaries).

All knowledge users and three researchers on the team took part in the start-up and planning and protocol development stages (Stages 1 and 3, [Figure 1](#)), where they contributed to defining the research question and approach and intervention protocol development. The majority of the additional knowledge-user informants (n=31/32) contributed to the content development and/or adaptation workshops of the intervention (Stages 2 and 4, [Figure 1](#)), which were also attended by some members of the research team in a research capacity. Workshop attendance among team knowledge-user partners and knowledge-user informants was determined by a combination of availability, geographical location and interest. To optimize participation when in-person workshop attendance was not possible, smaller workshops, individual interviews or teleconferencing into workshops were offered, where feasible. Limitations related to time and clinician availability meant one clinician knowledge-user informant inputted on the protocol in a mini workshop with another IKT partner between Stages 2 and 4.

Lessons learned

Benefits and facilitators of using IKT in my project

Throughout the project, the researchers in the team emphasized that some evidence-based elements of the intervention (namely, supervised

individually tailored exercise programs to improve cardiorespiratory fitness delivered via telehealth) were essential. However, they remained open to knowledge users' opinions and experiences, which informed how this research could be optimally applied in clinical practice.

From my perspective, the input from our partner with a lived experience of stroke facilitated the inclusion of additional strategies to support a common language, the willingness of stroke-survivor participants to share honestly during workshops and ensure the appropriateness of developed resources (both within workshops and for the intervention under design). I believe this greatly increased the IKT project's acceptability and accessibility. The clinicians on the research team identified key knowledge-user informants to be invited to participate in the intervention design and identified the importance of including them as early as possible. These collective contributions enhanced the project's relevance, representation and acceptability, and therefore (I anticipate) its potential outcomes.

The facilitators of using an IKT approach included:

- Working with researchers whose knowledge and support aided the IKT approach, workshop facilitation and communication support.
- An engaged and flexible research team that provided crucial feedback to shape the project's processes, outcomes and, ultimately, the intervention.

Barriers to using an IKT approach in my project

The perceived barriers to using an IKT approach were:

- Tight timelines: Our research team worked within a tight seven-month timeline dictated by my PhD program timeline. A lack of time created challenges related to: (1) recruiting diverse knowledge-user informants; (2) preparing knowledge-user partner team members on IKT and research processes, and identifying individual knowledge-user needs during the

partnership; and (3) having sufficient time between workshops to prepare materials and support research team communication.

- Unequal representation of knowledge-user groups: Our research team included one person with a lived experience of stroke. This limited the diversity of the stroke survivor voice and likely increased the burden on the sole stroke survivor member.
- Constraints of ethics approval processes: The project required time-intensive ethical amendments and governance applications, which added to the already demanding time pressure and sometimes limited the “iterative” IKT approach.
- Knowledge-user attendance at workshops: Knowledge users had their own personal and professional commitments and thus sometimes had limited capacity to attend workshops at designated times. This was a barrier particularly in workshops where the research team identified the need for a variety of knowledge-user groups to facilitate understanding of differing perspectives and decisions.
- Lack of funding to remunerate knowledge-user partners and knowledge-user informants: Our project had a very tight budget, which limited our ability to reimburse knowledge users for their time or expenses, which may have limited:

(1) the time knowledge users could contribute to the project, and therefore possibly the amount of input they provided; and (2) the diversity of the knowledge users we were able to engage in our project.

If given the opportunity, there are several elements I would alter to improve the use of an IKT approach in future projects:

- Increase time spent in the initiation of the project to ensure that the initial workshop better meets the needs of those involved (e.g., by identifying and implementing strategies that were applied “on the run,” such as supported conversation techniques and prioritizing content to reduce workshop length).
- I would more consistently seek feedback from the knowledge-user partners on the research team to ensure timelier implementation of strategies to improve the project and/or its processes to avoid rushed efforts to implement changes in response to feedback.
- Formally evaluate knowledge-user partner and informant engagement to help ensure and demonstrate genuine achievement (or lack of achievement) of shared decision-making and power.
- Increase the number of stroke survivors on the research team to allow more voices and diversity of voices of stroke survivors.

THREE RECOMMENDATIONS FOR TRAINEES

1

Use a facilitator independent of the research team to optimize participation in the IKT process. Where this is not possible, ensure you have adequate support to help overcome the challenge of simultaneously facilitating and participating in workshops.

2

Ensure adequate representation of knowledge-user groups to facilitate an equal voice for each, allow sharing of the roles and responsibilities and identify strategies to support individual knowledge users early in the initiation process of your project.

3

Regularly communicate with all knowledge users (partners and informants) for feedback to ensure the project's processes/design are optimal and that you are aware of knowledge users' competing demands and the project's impact so it can be managed/modified effectively, as needed.

CONCLUSIONS

Using an IKT approach enabled us to achieve the co-design of an evidence-based intervention within the constraints of a tight timeline. Elements of the intervention resulting from knowledge-user (knowledge-user partners and informants) input through the IKT approach included: increased therapist training; increased time allocated for intervention delivery; strategies to minimize the barriers related to the use of technology for telehealth, such as improved supports for stroke survivors (e.g., optional home visits, additional teleconference session before initiation of the exercise program and tailoring of equipment choices); and more appropriate and acceptable resources for the program's participants. Ultimately, these elements should help ensure the intervention can overcome barriers its future users are likely to face so it can be better implemented in research and clinical practice.

REFERENCES

1. English C, Healy GN, Coates A, Lewis L, Olds T, Bernhardt J. et al. Sitting and activity time in people with stroke. *Phys Ther*. 2016;96(2):193-201.
2. Fini NA, Holland AE, Keating J, Simek J, Bernhardt J. How physically active are people following stroke? Systematic review and quantitative synthesis. *Phys Ther*. 2017;97(7):707-717.
3. O'Donnell MJ, Chin SL, Rangarajan S, Xavier D, Liu L, Zhang H, et al. Global and regional effects of potentially modifiable risk factors associated with acute stroke in 32 countries (INTERSTROKE): a case-control study. *Lancet*. 2016;388(10046):761-775.
4. Turan TN, Al Kasab S, Nizam A, Lynn MJ, Harrell J, Derdeyn CP, et al. Relationship between risk factor control and compliance with a lifestyle modification program in the stenting aggressive medical management for prevention of recurrent stroke in intracranial stenosis trial. *J Stroke Cerebrovasc Dis*. 2018;27(3):801-805.
5. Deijle IA, Van Schaik SM, Van Wegen EEH, Weinstein HC, Kwakkel G, Van den Berg-Vos RM. Lifestyle interventions to prevent cardiovascular events after stroke and transient ischemic attack: systematic review and meta-analysis. *Stroke*. 2017;48(1):174-179.
6. D'Isabella NT, Shkredova DA, Richardson JA, Tang A. Effects of exercise on cardiovascular risk factors following stroke or transient ischemic attack: a systematic review and meta-analysis. *Clin Rehabil*. 2017;31(12):1561-1572.
7. Nicholson SL, Donaghy M, Johnston M, , Sniehotta FF, van Wijck F, Johnston D, et al. A qualitative theory guided analysis of stroke survivors' perceived barriers and facilitators to physical activity. *Disabil Rehabil*. 2014;36(22):1857-1868.
8. Marzolini S, Balitsky A, Jagroop D, Corbett D, Brooks D, Grace SL, et al. Factors affecting attendance at an adapted cardiac rehabilitation exercise program for individuals with mobility deficits poststroke. *J Stroke Cerebrovasc Dis*. 2016;25(1):87-94.
9. Walker MF, Hoffmann TC, Brady MC, Dean CM, Eng JJ, Farrin AJ, et al. Improving the development, monitoring and reporting of stroke rehabilitation research: consensus-based core recommendations from the Stroke Recovery and Rehabilitation Roundtable. *Neurorehabil Neural Repair*. 2017;31(10-11):877-884.
10. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ*. 2008;337:a1655.
11. Banner D, Bains M, Carroll S, Kandola DK, Rolfe DE, Wong C, et al. Patient and public engagement in integrated knowledge translation research: are we there yet? *Res Involv Engagem*. 2019;5:8.
12. Jull J, Graham ID, Kristjansson E, Moher D, Petkovic J, Yoganathan M, et al. Taking an integrated knowledge translation approach in research to develop the CONSORT-Equity 2017 reporting guideline: an observational study. *BMJ Open*. 2019;9(7):e026866.
13. Kothari A, Sibbald SL, Wathen CN. Evaluation of partnerships in a transnational family violence prevention network using an integrated knowledge translation and exchange model: a mixed methods study. *Health Res Policy Syst*. 2014;12:25.

ABOUT THE AUTHOR



EMILY RAMAGE is a PhD candidate at the School of Health Sciences, the University of Newcastle, Australia and is supported by an Australian Government Research Training Program Scholarship. Ms. Ramage's other affiliations include the Priority Research Centre for Stroke and Brain Injury, Newcastle, Australia, the Integrated Knowledge Translation Research Network (trainee), Australian Institute for Musculoskeletal Science (member in training), and the Centre of Research Excellence in Stroke Rehabilitation and Brain Recovery, Hunter Medical Research Institute, Newcastle, Australia. Her doctoral studies are supervised by Prof. Coralie English (principal supervisor), A/Prof. Catherine Said, Dr. Elizabeth Lynch and Dr. Amanda Patterson. Ms. Ramage is also a practicing clinical physiotherapist with 15 years' experience, predominantly in the area of neurological rehabilitation. Her research interests include stroke rehabilitation and recovery, physical activity knowledge translation and co-design.

Piloting co-design in a humanitarian setting: New insights and lessons learned – the importance of cultural and contextual adaptation

Ilja Ormel¹, Susan Law^{2,3}

¹McGill University; ²Institute for Better Health, Trillium Health Partners; ³University of Toronto

INTRODUCTION

The primary motivation for my PhD research was to explore the value of an integrated knowledge translation (IKT) approach in settings where populations receive humanitarian aid after crises such as earthquakes and disease outbreaks. To date, there is limited evidence of the application of participatory research in humanitarian settings. If organizations providing humanitarian assistance around the world are serious about aligning local action with the new wave of accountability and engagement rhetoric, there is a need to develop and test appropriate research approaches that engage local populations. My thesis research explores how the experiences of cholera-affected populations in Haiti can help to inform and improve future hygiene promotion efforts. The humanitarian response to cholera started nine months after the 2010 earthquake and involved key agencies such as the Ministry of Public Health, National Directorate of Drinking Water and Sanitation, UNICEF and national as well as international non-governmental organizations (NGOs).

The NGO Action Contre la Faim (ACF) noted that their hygiene promotion efforts had not sufficiently resulted in the desired behaviour changes (e.g., washing hands, good defecation practices) and was interested in new ways of approaching the problem. For my doctoral research, I worked together with knowledge users (national and international staff members from ACF) engaged throughout the research process

(design, protocol writing, analysis and report writing), and involved local communities to gather perspectives and experiences with cholera. We informed key stakeholders such as other NGOs and governmental agencies of our research initiative and shared our research results with them.

DESCRIPTION OF THE IKT EXPERIENCE

Research in humanitarian settings can be challenging for many reasons, including security concerns, access issues and visa requirements. I was well aware of these challenges and spent a year contacting humanitarian organizations and searching for an appropriate opportunity that would bring together my interests in participatory approaches, health experiences research and humanitarian work. In the end, I succeeded in finding a research project through a friend who sent me a notice regarding an unpaid position with ACF to conduct a survey to better understand the perceptions of the cholera-affected populations in Haiti.

My initial contact was with ACF's technical advisor at their head office in New York, who then organized a telephone meeting with national staff members (project manager and deputy coordinator) responsible for the cholera response. Further communication was initially by email with the aim to rapidly submit the research proposal. Together we adapted the proposed survey design to an IKT-inspired co-design approach, which I believed had more potential to address their

objectives. During this process I was guided by the experience and knowledge of my PhD committee, which included members with years of experience with IKT approaches. We identified many different stakeholders (e.g., different governmental agencies, NGOs, traditional healers) who were actively involved in the cholera response. While ACF's national and international staff members were identified as the project's main knowledge users, I made an effort to inform additional key stakeholders (e.g., other NGOs and governmental agencies) of our research initiative. Once I arrived in the field, I asked for input on the proposed research approach from the 20 national staff members responsible for the health promotion activities. Together we worked to integrate more culturally appropriate methods (e.g., to conduct focus group discussions rather than individual interviews) and to report back to communities so as to mitigate past criticism related to "helicopter" approaches. In addition, in light of emerging results and NGO organizational challenges, the planned implementation phase was truncated and the NGO unexpectedly requested a report of the results within a short timeframe. It took me some time to realize the value of providing rapid results through reporting, especially in humanitarian emergency responses.

Lessons learned

Some key challenges, including high staff turnover and the NGO's dependency on external funding, had a great influence on the progress of the research project. In particular, it was difficult to ensure that results continued to be implemented in practice, partly because of staff turnover. Both the project and research activities stopped when ACF did not receive further external funding.

As a PhD student, my confidence in the IKT field was at times challenged, particularly when needing to negotiate adaptations to the plan to progress in a way that respected all of the project's knowledge users. I learned that these challenges did not necessarily mean that the

research plan had failed. My confidence in an IKT approach was strengthened due to the quality of the experiential knowledge collected with limited resources. Moreover, learning to adapt my expectations helped me to see the larger context for changing practice and the importance of being flexible and responsive to local conditions and contexts in the field. This flexibility contributed to greater trust and constructive relationships with knowledge users. For example, the local research assistant greatly appreciated that, as a result of his arguments and insights, we decided to change the research approach from interviews to focus groups. In another instance, I collaborated closely with one of the knowledge users on a presentation of the research results. Overall, the IKT approach facilitated mutual learning, better presentation of the data and adaptations to the final stages of the research.

Our approach was not equally embraced by all key stakeholders. In particular, the manager of the coordinating NGO was very skeptical of listening to affected populations and collaborating with knowledge users, as he was concerned that doing so risked providing the communities with wrong ideas (i.e., that eradication was not possible). We did take his concerns into account but did not see any problem in continuing our activities. Engaging traditional healers was challenging as they were spread out and we were unable to provide monetary compensation for attendance (participants received a meal after attendance). Eventually we were able to organize a focus group with several traditional healers and their assistants, who suggested that they would be in a good position to hand out oral rehydration solutions to sick people who were seen by them before reaching the health centres.

CONCLUSIONS

There is an urgent need to develop IKT approaches in designing and evaluating responses to population needs in humanitarian contexts and to learn from the implementation of

IKT approaches in these settings. While this project ended before implementation, the benefits of the IKT approach included improved collaboration, trust and accountability for affected populations. My research approach required changes that I initially felt were not possible. Despite related challenges, I learned that IKT collaboration can produce new knowledge that is highly valuable to local communities and the people who lead change. The data resulting from the research helped to equip the knowledge users and research team with experiential knowledge and information regarding the ways in which

hygiene promotion interventions can be improved. I would recommend that other trainees openly discuss and clarify expectations (e.g., outputs, deadlines, etc.) with knowledge users at the start of the research, enjoy the process of mutual learning and exchange, and explore whether/how adaptations to a given approach might produce more valuable knowledge and results. Being responsive to knowledge users in terms of design and methods, and embracing the unanticipated, will likely produce different but more meaningful results.

THREE RECOMMENDATIONS FOR TRAINEES

- 1 Openly discuss and clarify expectations (e.g., outputs, deadlines, etc.) with knowledge users at the start of the research.
- 2 Enjoy the process of mutual learning and exchange.
- 3 Explore whether/how adaptations to a given approach might produce more valuable knowledge and results.

ABOUT THE AUTHOR



ILJA ORMEL is a humanitarian worker and senior qualitative researcher who is completing her PhD entitled *A partnership approach to improving humanitarian aid: patient and community narratives of cholera* at McGill University (Department of Family Medicine, Canada) under the supervision of Drs. Law and Macaulay. This thesis brings together her work experience in humanitarian disease outbreaks such as Ebola and cholera and her research experience using participative approaches and illness narratives (published on www.healthexperiences.ca). Her thesis research was launched with financial support from Dr. Graham's CIHR Foundation grant: *Moving knowledge into action for more effective practice, programs and policy: A research program focusing on integrated knowledge translation* followed by a FRQS doctorate funding. She is interested to continue promoting the use of IKT and other participatory approaches in research in humanitarian aid programs.

Working together towards impact: An integrated knowledge translation initiative aimed at health-care providers

Aislinn Conway¹⁻³, Maura Dowling⁴, Áine Binchy^{4,5}, Jane Grosvenor⁵, Margaret Coohill⁵,
Deirdre Naughton^{4,5}, Jean James^{4,5}, Declan Devane^{4,6}

¹University of Ottawa; ²Better Outcomes Registry & Network (BORN) Ontario;

³CHEO Research Institute; ⁴National University of Ireland Galway; ⁵University Hospital Galway; ⁶Health Research Board Trials Methodology Research Network

INTRODUCTION

My first integrated knowledge translation (IKT) role began in 2010 when I worked as a Clinical Evidence Based Information Service Specialist at a National Health Service hospital in the United Kingdom. This job involved partnering with point-of-care staff in the women and children's division to respond to their informational needs. I collaborated with them to bridge the evidence-to-practice gap by attending ward rounds and clinical handovers to identify evidence gaps, producing evidence summaries, assisting in developing new and updated clinical practice guidelines, etc. I also co-ordinated Evidence in Practice Group sessions in partnership with health-care providers exploring evidence on topics and clinical queries chosen by staff. It was through this role that my interest in IKT developed and I subsequently decided to pursue a PhD at the National University of Ireland, Galway, funded by the Health Research Board Trials Methodology Research Network. The case reported here and completed in 2018, was part of my doctoral work.

This IKT project was called Evidence Rounds and the overall goal was to develop and implement an initiative to address the evidence-to-practice gap at an urban hospital in Ireland. The knowledge users were health-care providers working in the neonatal and obstetric departments. In addition to myself, the project team was composed of two academic researchers and five knowledge users

(nurses and midwives working in the neonatal and obstetric departments) who made up an on-site implementation team. The project featured three core components: (1) six group sessions over nine months exploring evidence on clinical topics; (2) a dedicated project website, which acted as a repository for evidence and related information; and (3) a knowledge translation professional, which was my role. Because of the IKT approach, the knowledge users identified evidence relating to their practice and chose each of the six clinical topics. We used the Knowledge Translation Planning Template¹ as a planning tool and Lavis's organizing framework for knowledge transfer² to describe the initiative. We documented the Evidence Rounds implementation process using the Template for Intervention Description and Replication (TIDieR) checklist.³ This IKT project involved both collaboration (whereby the researcher or the knowledge user had a greater role in a task) and partnership (the knowledge user and researcher shared tasks). Our approach was informed by Roger's diffusion of innovations theory, which categorizes stakeholders who adopt innovations over time into: (1) innovators, (2) early adopters, (3) early majority, (4) late majority and (5) laggards.⁴

DESCRIPTION OF THE IKT EXPERIENCE

Engagement with knowledge users began at the outset. The IKT partnership was established during the planning phase by reaching out to key

informants within the targeted hospital departments and through word-of-mouth recommendations. We then connected with nursing and midwifery staff who expressed an interest in the project, some of whom became members of our implementation team. They contributed to the design of the initiative and were our partners in implementing the initiative. Three knowledge users (both project team members and beyond the team) presented at each session and presenters were identified through word-of-mouth recommendations and requests for volunteers. To find out more about Evidence Rounds from a knowledge-user perspective, we invited those who attended or presented at a minimum of one Evidence Rounds session to take part in a focus group or interview.

As the Knowledge Translation Specialist, I was involved in all stages of the conceptualization, planning and implementation of the initiative, including designing educational sessions, creating and maintaining the website, formulating and conducting search strategies, arranging meetings with presenters, advising on presentation content, conducting focus groups and interviews, and data analysis. My supervisor, Professor Declan Devane, provided invaluable guidance and input during conceptualization and throughout the entire project. Dr. Maura Dowling advised on qualitative methods and methodology, framework analysis⁵ and analyzed data.

The excellent core implementation team of five knowledge users helped with organizational activities, recruited presenters, promoted the project to their colleagues providing frontline care, took part in group presentations and were involved in processes to ensure the implementation of evidence. The wider group of knowledge users chose all six clinical topics covered during the project. Some of these presented official guidance and explored evidence on topics during group sessions. At the end of

each presentation, all staff in attendance were invited to partake in a discussion forum about the evidence and its applicability to the local context. They identified resulting actions that were assigned to individuals or the group. Knowledge users were responsible for the implementation of the evidence into practice and policy because of their status as employees in the relevant departments.

We followed up with the implementation team to investigate whether Evidence Rounds had impacted local policy and clinical practice at three, 16 and 21 months after the final session. We found that Evidence Rounds increased staff awareness of research evidence and local audit data, and contributed to changes in medication labelling, updated staff guidance and changes in the management of preterm births. Most of the evidence was implemented by the third round of follow-up, which indicates the complex nature of health systems and delayed change processes.

The knowledge users on the project team and the researchers co-authored a peer-reviewed publication describing the implementation of the initiative and its impact.

Lessons learned

Although Evidence Rounds contributed to changes in patient care and updated local policy, a key challenge encountered during our project was the issue of sustainability. Throughout the implementation of the Evidence Rounds initiative, I encouraged discussion of the issue of sustainability with the implementation team and wider knowledge-user group. Given the time-limited nature of the doctoral project, it was important to design processes to make handover of the Evidence Rounds project easier when I left the project. However, despite informal sustainability planning discussion, proof of impact of the project and willingness from team members to continue the initiative, the project

could not achieve sustainability without adequate funding and resources.

One benefit of the IKT process and our partnership with knowledge users was the ability for the researchers to learn about the preferences of the staff for whom the intervention was intended. For example, through discussions with the knowledge users on the team and broader knowledge-user engagement (via focus groups, interviews and the project website), we learned staff had wide-ranging preferences in how to receive information, evidence and correspondence. This engagement with knowledge users from the beginning of the IKT project led to the use of multiple modes of delivery to address staff needs.

One strategy that I found beneficial was the use of a logic model. I created a process-oriented logic model at the planning stage and updated it iteratively. Not only did this model help to keep the project on track, it was also a useful visual tool to help potential new members of the project team and other stakeholders gain an understanding of the processes and desired impact of the IKT project.

CONCLUSIONS

In this project, we used an IKT approach to co-produce and co-implement the Evidence Rounds project, resulting in an initiative that was tailored

and adapted to meet the needs and preferences of knowledge users. It is not clear how this approach affected the duration, outputs or application of the knowledge shared within the project because it would have been a comparatively different project without them. We believe that successful engagement with the core implementation team and the wider knowledge-user group led to implementation of evidence, which otherwise would have been extremely difficult or unlikely because none of the researchers on the team were clinicians based at the hospital.

I have three important recommendations to share with other trainee researchers using IKT approaches. First, I recommend working with knowledge users who are early adopters demonstrating enthusiasm from the start, while welcoming others to join for their own reasons at varying times throughout the project. We found that some individuals who were reluctant to buy into Evidence Rounds during the initial planning phase later became important champions for the project. Second, I recommend leveraging your team's networks to begin identifying potential knowledge users to join your project team. We identified the early adopters through Professor Devane's professional connections having worked in the hospital and through word of mouth recommendations from the early adopters themselves. Third, invest a substantial amount of

THREE RECOMMENDATIONS FOR TRAINEES

- 1** Work with knowledge users who are early adopters demonstrating enthusiasm from the start and work to optimize the project together, while welcoming others to join for their own reasons at varying times throughout the project.
- 2** Leverage your team's networks to begin identifying potential knowledge users to join your project team.
- 3** Invest a substantial amount of time in co-designing the project with a core team of knowledge users, then involve a wider group of knowledge users as much as possible.

time in co-designing the project with a core team of knowledge users, then involve a wider group of knowledge users as much as possible. Health systems and the processes of adoption and behaviour change are complex. We appreciated all contributions and worked hard together towards the shared goal of improving patient care. Our knowledge users were central to our IKT initiative because they were involved in the planning, delivery, decision-making processes and ultimately, the implementation of evidence. We found this approach to IKT led to a very worthwhile and rewarding experience.

You can read more about Evidence Rounds in two companion papers published in 2019 describing its implementation, impact and the results of focus groups and interviews about the initiative with knowledge users.^{6,7}

REFERENCES

1. Barwick M. Knowledge translation planning template. Toronto, ON: The Hospital for Sick Children; 2008, 2013.
2. Lavis JN, Robertson D, Woodside JM, McLeod CB, Abelson J, Knowledge Transfer Study Group. How can research organizations more effectively transfer research knowledge to decision makers? *Milbank Q.* 2003;81(2):221–248, 171–172.
3. Hoffmann TC, Glasziou PP, Boutron I, Milne R, Perera R, Moher D, et al. Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. *BMJ.* 2014;348:g1687.
4. Rogers EM. *Diffusion of Innovations*. 3rd edition. New York: The Free Press; 1983.
5. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess RG, eds. *Analysing Qualitative Data*. London: Routledge; 1994. p. 173–194.
6. Conway A, Dowling M, Binchy Á, Grosvenor J, Coohill M, Naughton D, et al. Implementing an initiative to promote evidence-informed practice: part 1 - a description of the Evidence Rounds programme. *BMC Med Educ.* 2019;19(1):74.
7. Conway A, Dowling M, Devane D. Implementing an initiative promote evidence-informed practice: part 2 - healthcare professionals' perspectives of the Evidence Rounds programme. *BMC Med Educ.* 2019;19(1):75.

ABOUT THE AUTHOR



DR. AISLINN CONWAY is a post-doctoral fellow at the Better Outcomes Registry & Network (BORN) Ontario, currently undertaking a Health System Impact Fellowship, co-funded by the CIHR Institute of Health Services and Policy Research and the CHEO Research Institute in Ottawa, Canada. In 2010, Dr. Conway was first introduced to integrated knowledge translation (IKT) while working for the National Health Service in the United Kingdom and went on to complete a PhD at the National University of Ireland, Galway involving an IKT project inspired by this work. She is currently affiliated with BORN Ontario, the CHEO Research Institute and the University of Ottawa. Dr. Conway's research interests include IKT, evidence-informed practice, obstetric safety, and dissemination and implementation practice and science.

Does early engagement of knowledge users support uptake of research findings in a dynamic health environment?

An integrated knowledge translation case

Nedra Peter¹, Anita Kothari¹, Nancy Murray², Ruta Valaitis², on behalf of the *Does Early Engagement of Knowledge Users Support Uptake of Strategies for Local Health Integration Networks and Public Health Agencies Collaboration?* research team

¹Western University; ²McMaster University

INTRODUCTION

Trainee

Dr. Nedra Peter is a post-doctoral associate at Western University in the Faculty of Health Sciences. Dr. Peter first became familiar with the concept of IKT while assisting on a previous study based out of a research institute in Ottawa, which sought to understand the contributions of five systems-level research projects. The study found that the research institute engages in IKT through their management and steering committee, which provides hands-on support to researchers. This support includes collaborating on identifying research questions and ensuring that the knowledge and tools developed by researchers are relevant, practical and valuable to the corresponding sector.¹ Through this work, Dr. Peter discovered how research impact could be enhanced using an IKT approach. Dr. Peter was then hired as a research assistant to work on a project titled *Does Early Engagement of Knowledge Users Support Uptake of Strategies for Local Health Integration Networks and Public Health Agencies Collaboration?*

Project

In 2016, the Patients First Act was passed in Ontario. This Act required public health agencies to work collaboratively with local health planning agencies using a population health approach. The aim was to improve access to primary health care

by planning services that met the health needs of the entire community. A research project, *Strengthening a Population Health Approach for Health System Planning*, hereafter called “the Project,” was conducted to examine the key elements of a successful collaboration between regional health authorities and public health agencies. The Project's research team consisted of six representatives from public health units across Ontario, one representative from a regional health authority and four academic researchers. Two working groups were established: one group focused on the qualitative aspects of the Project, while the other group focused on the quantitative aspects. The groups were chosen based on team members' expertise. For example, an epidemiologist on the team joined the quantitative group. The Project's knowledge users included individuals from various provincial-level public health strategic committees (n=2) and organizations (n=5). The knowledge users served an advisory role to the Project. Through presentations and dialogue they contributed to the development of the Project's funding proposal and were engaged throughout the conduct of the study.

The IKT case reported here is based on what can be considered a case study of the Project. The aim of the case study was to understand how early engagement of knowledge users in the Project

influenced the use and impact of the research findings.

DESCRIPTION OF THE IKT EXPERIENCE

Upon completion of the Project, the primary knowledge users wanted to know whether their early engagement was effective and whether they should use it in future work. This led to the decision to undertake a case study of the Project. The case study team comprised the IKT trainee, Nedra Peter, and the original members of the Project's research team (both the researchers and the knowledge users), who together now became the primary knowledge users on the case study research team. The case study adopted an IKT approach, where the IKT trainee and the Project team members (the knowledge users for this case study) determined the research questions and data collection methods collaboratively. The case study received research ethics approval from Western University.

The methods for the case study were informed by Kok and Schuit's contribution mapping framework.² Data collection involved conducting an in-person meeting with the Project's team members (the knowledge users for this case study). During this meeting, the Project's research team mapped out anticipated contributions in relation to capacity, activities and impacts; the IKT trainee facilitated this process. The Project's knowledge users (individuals on the provincial-level public health strategic committees) were also interviewed by the IKT trainee to solicit reactions, fill gaps and confirm early impacts. The case study knowledge users provided feedback on iterative data analysis about the impact of early engagement and related research products through monthly meetings via videoconferences. Meetings were supplemented with print summaries of findings, and meeting notes were created and distributed. This collaboration is ongoing as the case study team works to develop a manuscript.

The Project outputs included indicators of collaboration, a one-page summary and a report on recommendations for a vision, values and principles for working with local health planning agencies. These products provide a framework for decision-making in the health sector and could be used to guide new relationships between public health agencies and regional health authorities. Results of the case study indicated that the findings from the Project were not taken up by all knowledge users. The main expected impact, as reported by participants, was that the indicators will improve collaborations in the health sectors. Case study findings revealed that the health system context was undergoing unexpected change, and there was not enough engagement with regional health authorities.

The IKT case study revealed two key factors that facilitated awareness of the Project's research findings – pre-established relationships with the Project's public health knowledge users and ongoing discussions during the Project. The Project team used early engagement strategies to reach out to key committees and organizations (the knowledge users) and included them from the formulation of the research project through to the dissemination of the findings. Case study participants expected that the impact of the Project would be improved because of this continuous and ongoing engagement process. However, they also thought that the emphasis on front-end engagement resulted in less attention to the dissemination plan after the Project was done.

Lessons learned

A key factor that positively influenced the IKT process in the case study was that the majority of the research team's members already had well-established relationships from the two years they spent working on the Project. These relationships supported valuing different perspectives and facilitated a mutual understanding of team member language, work style, needs and constraints. The significance of these pre-

established relationships among the case study knowledge users highlights the considerable time and effort needed to establish functional partnerships for efficient collaborative research.

An operational challenge in using an IKT approach for the case study was involving all members of the Project's research team equally. Due to previous engagements or time constraints, some team members were unable to attend every case study team meeting, but they were later provided with meeting notes. By the time the case study was being conducted, the Project team members had already been participating in primary data collection and participating in the case study added another year to their research engagement. Over time, some Project team members retired or took on new jobs, resulting in heavier workloads for those remaining on the Project's research team. Setting firm dates for deliverables encouraged the production of outputs at various stages of the research.

For the case study, the Project research team members changed roles and became knowledge users. Due to holding the dual role as researchers and knowledge users, the case study knowledge users served as "bridgers" between the research being conducted and the health sector. Therefore, the case study research team could help align the research to decision makers' evolving concerns. As bridgers, the case study research team aligned the study outputs with the changing political and practice environment; the team was able to adapt to maintain the relevance of the research because of the partnerships formed between researchers, managers and staff. This dual role also presented a methodological challenge; as members of the Project research team they could be more inclined to emphasize the positive outcomes.

This challenge was mitigated by involving an outsider, the IKT trainee, which allowed the Project team to evaluate their work from a distance, resulting in a more rigorous process. Although the

team faced challenges with the dynamic context of the research environment, from the perspective of the trainee, the IKT process was positive with limited challenges. As a trainee engaging in an IKT approach, it was beneficial to develop and follow a long-term engagement plan that accounted for the research partners having adequate time to provide in-depth feedback and for maintaining regular communication with the research partners.

CONCLUSIONS

Using an IKT approach has been beneficial for the development of relevant research and an early engagement strategy in the Project. Subsequently, an IKT approach was beneficial for the evaluation of the impact of the Project. The partnership in the case continues long after the expectations of the funding agreement, as the team continues to develop a manuscript for publication. The long-term uptake of the research products is expected to be high, as the research question and positioning of the findings are relevant for decision-making.

THREE RECOMMENDATIONS FOR TRAINEES

- 1 Invest time in developing and building relationships with decision makers.
- 2 Address the research questions for which the decision makers seek answers.
- 3 Consider the socio-political context in which the decision-making will occur.

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REFERENCES

1. Kothari A, Peter N, Donskov M, Luciani T. Research impact of systems-level long-term care research: a multiple case study. *Health Res Policy Syst.* 2017;15(1):23.
2. Kok MO, Schuit AJ. Contribution mapping: a method for mapping the contribution of research to enhance its impact. *Health Res Policy Syst.* 2012;10:21.

ABOUT THE AUTHOR



DR. NEDRA PETER is a post-doctoral fellow with the Integrated Knowledge Translation Research Network (IKTRN) at the Knowledge Translation Laboratory at Western University. She is supervised by Drs. Anita Kothari and Ian Graham. Her research interests include using integrated knowledge translation approaches to set priorities for research in the third sector, in particular, organizations who support youth living in poverty. Dr. Peter's research aims to: (1) establish and build relationships with third sector organizations who support youth living in poverty; (2) collaboratively determine research priorities related to youth poverty; (3) collaboratively develop an integrated knowledge translation action plan to advance the research agenda on youth poverty; and (4) assess participating third sector organizations' experiences with the IKT process.

